

CHILDREN'S REHABILITATIVE SERVICES

2008 FAMILY CENTERED SURVEY

EXECUTIVE SUMMARY

The mission of the ADHS Children's Rehabilitative Services (CRS) program is to improve the quality of life for children by providing family centered medical treatment, rehabilitation, and related support services to enrolled individuals who have certain medical, handicapping, or potentially handicapping conditions. The family is the most important participant in the system of care for children with special healthcare needs (CSHCN). Thus, a family's perception of the services received through the CRS program is crucial to its administration. The Family Centered Survey was created to evaluate the satisfaction of member families and is conducted annually.

Key Findings from the 2008 Family Centered Survey

- Overall, CRS care was rated at an average of 9.0 on a 10-point scale (with 10 being the highest level).
- The majority of respondents (89%) reported that they were satisfied or very satisfied with how long it took to get urgent care.
- Seventy-five percent of respondents were able to obtain an appointment with a specialist within 45 days which was significantly higher than 63 percent reported in 2007.
- The average time of 31 days that participants reported waiting to get an appointment at a CRS clinic was a significant improvement from the 2007 average of 51 days.
- The majority of respondents (88.5%) reported waiting times in the office were within the AHCCCS standard of 45 min.
- Over the past two years, there has been a steady increase in families who felt they were well-informed, involved in decision making, and were treated with courtesy and respect by CRS doctors and clinic staff.
- When compared to 2007 results, there was a significant increase in the percentage of respondents, especially among Hispanic and minority families, who agreed or strongly agreed that the CRS staff had respect for the family's religious/spiritual beliefs and were sensitive to the family's cultural/ethnic background.

AMENDMENT

In August of 2009, CRSA discovered that some of the questions reported in the 2008 Family Centered Survey were based upon preliminary results rather than final results. Consequently, the results for nine questions (Q22-Q30) were updated in Appendix C (Survey Responses, Statewide) and Appendix D (Survey Responses by Site). Additionally, updates were made to the body of the report. Please see the table below for the revisions.

Question	Table/Figure/Page Number	2008 (old)	2008 (revised)
Q22	Table 2, Page 12	82.5%	82.0%
Q24	Page 12	44.5%, CI=37.6, 51.4	53%, CI=47.2, 58.9
Q25	Figure 6, Page 12, 13	92.1%	89.2%
Q26	Figure 7, Page 13	89.8%	87.8%
Q27	Figure 8, Page 14	98.9%	96.6%
Q28	Page 5, 17	9.1 (CI=8.8, 9.2)	9.0 (CI=8.8, 9.2)
Q29	Page 14	32.0%	27.0%
Q30	Page 14	92.1%	93.2%

INTRODUCTION

The mission of the ADHS Children's Rehabilitative Services (CRS) program is to improve the quality of life for children by providing family centered medical treatment, rehabilitation, and related support services to enrolled individuals who have certain medical, handicapping, or potentially handicapping conditions. CRS specialists manage the overall care for what are often complicated medical conditions leading to more appropriate utilization of services and minimizing the need for emergency care. Four regional clinics throughout Arizona provide multi-specialty, interdisciplinary care to enrolled members.

The family is the most important participant in the system of care for children with special healthcare needs (CSHCN). Thus, a family's perception of the services received through the CRS program is crucial to its administration. The Family Centered Survey was created to evaluate the satisfaction of member families and is conducted annually.

The 2008 survey tool continues to be based on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with modifications to accommodate the special population and program characteristics of CRS. The telephone survey was administered to a representative sample of active AHCCCS-enrolled CRS members under the age of 21. This year, the overall response rate was 46 percent.

The mean age of children represented by respondents was 9.2 years, with nearly 64 percent of children between the ages of four and fourteen. Fifty-one percent were male, and 58 percent were of Hispanic or Latino descent. Most of the members (55.4%) spoke English as their main language at home, with an additional 11.7 percent speaking mainly Spanish at home. The most common diagnostic conditions were related to nervous system, circulatory system, and

musculoskeletal/connective tissue disorders. More demographic data on respondents can be found in Appendix A.

Results from the 2008 survey will be presented in the following sections. Ninety-five percent confidence intervals are denoted by \pm CI. Throughout the document, the number of each question is listed in parentheses to provide for a quick reference to material in the appendices. Please see Appendix A for a description of the study methodology, Appendix B for a copy of the survey tool, Appendix C for a complete breakdown of the responses statewide, Appendix D for a comparison of responses by site, and Appendix E for an evaluation of cultural competency.

OVERALL HEALTH AND RATINGS OF CARE

Overall Care

Respondents were asked to rate their child's overall health on a five-point scale ranging from excellent to poor (Q31). Nearly 63% of respondents characterized their children's health as excellent or very good, with an additional 27% reporting a health rating of good. Ten percent of respondents characterized their child's health as fair or poor. When asked to rate the overall CRS health care (Q28), with 0 being the worst health care possible and 10 being the best health care possible, the average rating was 9.0 (CI=8.8, 9.2). Differences in ratings between contractor sites were not statistically significant, nor were there any differences from the 2007 average rating (9.0).

Specialty Care

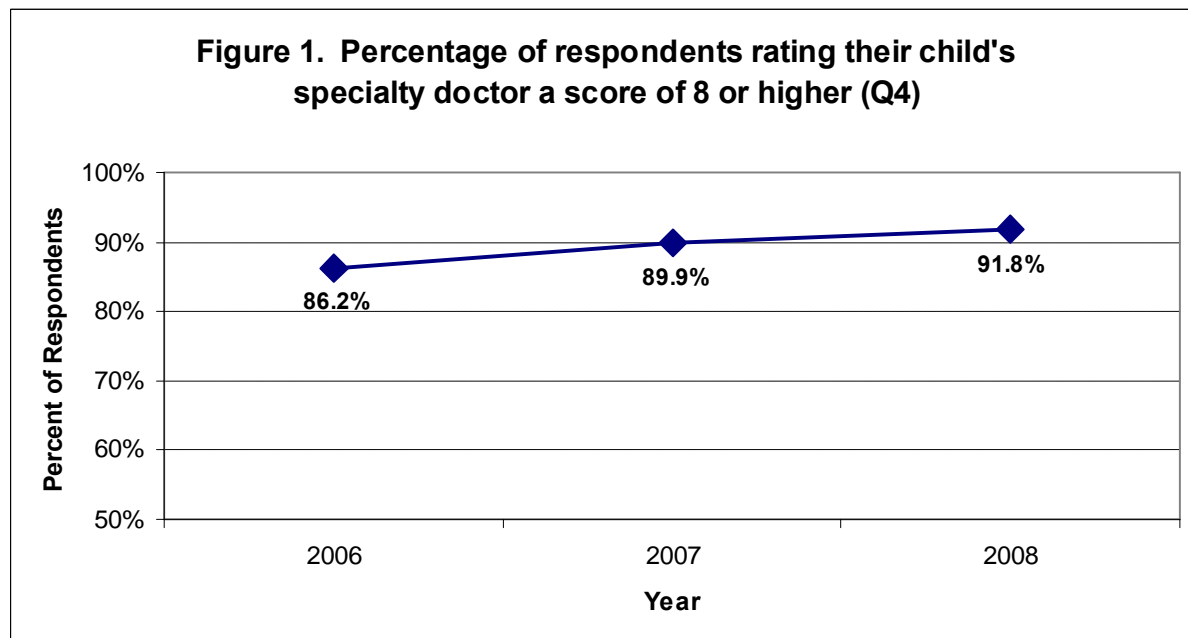
As seen in Table 1, 82 percent of members had seen a CRS specialist in the past 12 months (Q1). Of those members who did not see a CRS specialist, only 18 percent had attempted to get an appointment (Q2). Most parents/guardians (81.9%) reported that it was not a problem to

see a CRS specialist when needed, 7.6 percent said it was a small problem, and 10.5 percent said it was a big problem (Q3).

Table 1. Questions Related to Specialty Care

Question	2006	2007	2008
Q1. Saw a CRS specialty doctor in the last 12 months.	85%	86%	82%
Q2. Tried to get an appointment with a CRS specialty doctor in the last 12 months.	23%	10%	18%
Q3. It was not a problem to see a CRS specialty doctor that your child needed to see in the last 12 months.	77%	80%	82%
Q4. What number would you use to rate your child's specialty doctor?	8.9	9.0	9.2

The average rating on a scale from 0 to 10, with 10 being the best specialist possible, was 9.2 (CI=9.0, 9.4). Ninety-two percent of respondents gave their child's specialist a score of 8 or higher (Q4). The differences between results from 2007 to 2008 were not statistically significant. However, there was a significant difference when comparing 2006 to 2008 results. In 2006, 86.2 percent of the respondents gave their child's specialist a score of 8 or higher (see Figure 1).



ACCESS TO CARE

Forty-four percent of respondents called the CRS clinic during regular clinic hours to get help or advice for their child (Q5), the majority of whom (80%) reported usually or always getting the help or advice they needed (Q6).

Respondents were also asked about the number of emergency room visits made by their child. Less than 22 percent reported that their children visited an emergency room for their CRS condition (Q9).

AHCCCS has appointment standards for both primary care and specialty care. All of the care delivered at CRS clinics is specialty care, and only those AHCCCS standards that relate specifically to specialty care apply to CRS. The following standards are outlined in the AHCCCS contract with CRS:

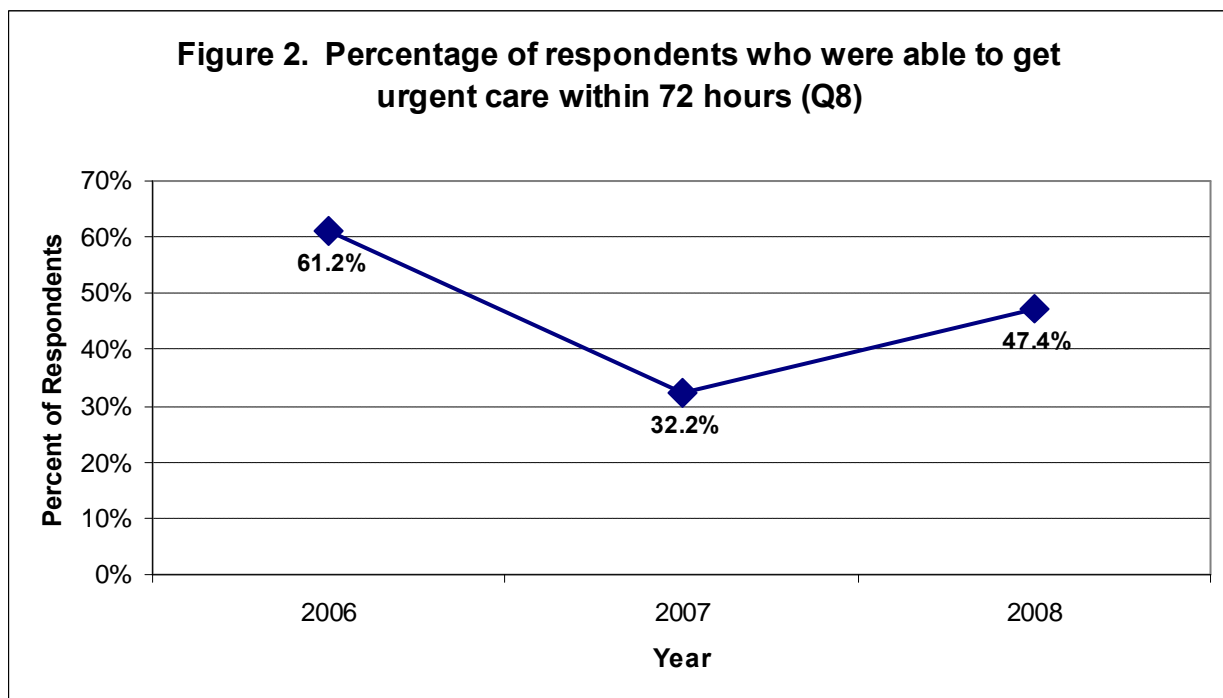
- For a CRS recipient with a medically urgent need, the CRS recipient must be seen according to the needs of the member and no later than 72 hours from the request.
- All other clinic appointments must be scheduled within 45 calendar days or less of referral, depending on the need of the CRS recipient's medical condition.
- A recipient's waiting time for an appointment must not exceed 45 minutes, unless the provider is unavailable due to an emergency.

47.4% Received Urgent Care within 72 Hours

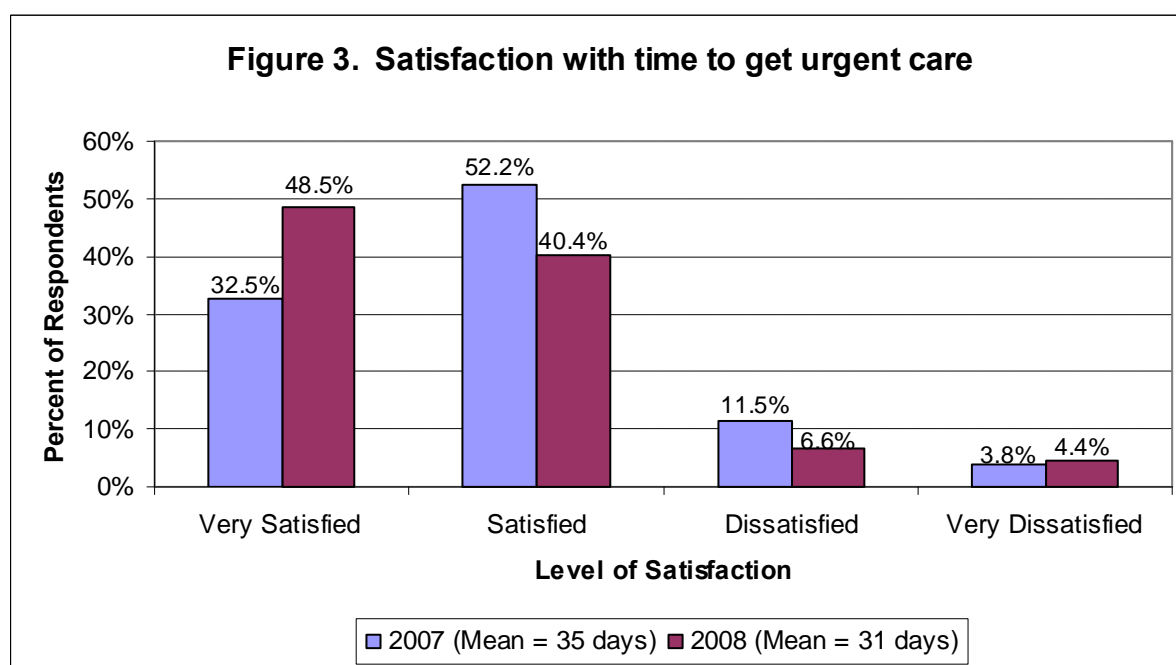
Urgent requests may involve conditions that are not covered under CRS, in which case the patient is referred back to the primary care physician. When the condition is covered by CRS, a determination is made as to what kind of need the patient has, and whether it is more appropriate to go to a physician's office or be seen at a clinic at the next scheduled visit.

Survey respondents were asked whether in the past year their children “needed care right away for their CRS condition” (Q7) and if so, how long they had to wait to get care at a CRS clinic (Q8). These questions were used to assess compliance with the AHCCCS urgent care standard, although there may be limitations to their applicability since CRS clinics do not provide urgent care in the usual sense of the word. Also, needing “care right away” may not have been interpreted by respondents as meaning “urgent care.”

More than half of the respondents (57.8%) reported that their child did not need urgent care for their CRS condition. Of those who needed urgent care in 2008, 47.4 percent (CI= 38.9, 55.9) said they were able to get it in a CRS clinic within 72 hours (Q8). This was significantly higher from 2007, where 32.2 percent were able to get urgent care at a CRS clinic within 72 hours (see Figure 2). Differences in 2008 compliance rates between contractor sites were not statistically significant.

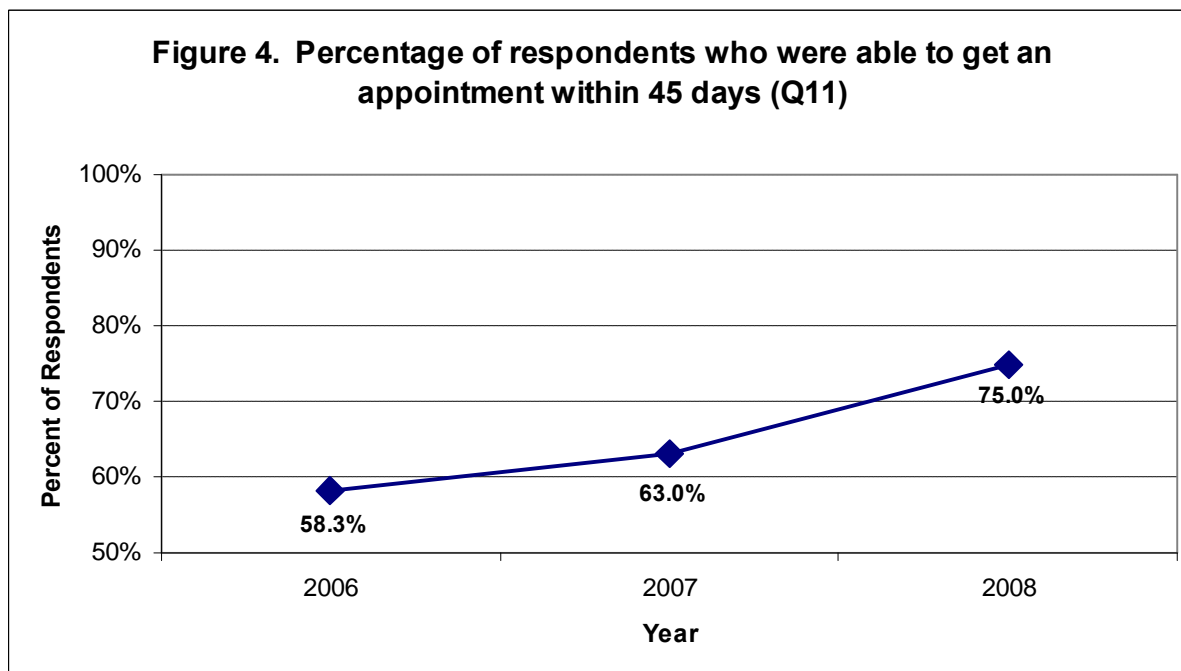


The majority of respondents (89%) reported being satisfied or very satisfied with how long it took to get urgent care (Q7). There were no significant differences in satisfaction level by site. The percentage of respondents who were very satisfied with the time to get urgent care was significantly higher in 2008 (48.5%) than in 2007 (32.5%, see Figure 3). Among the very satisfied respondents, 62 percent received urgent care within 3 days. The average time reported to get urgent care was 31 days, with responses ranging from one day to one year.

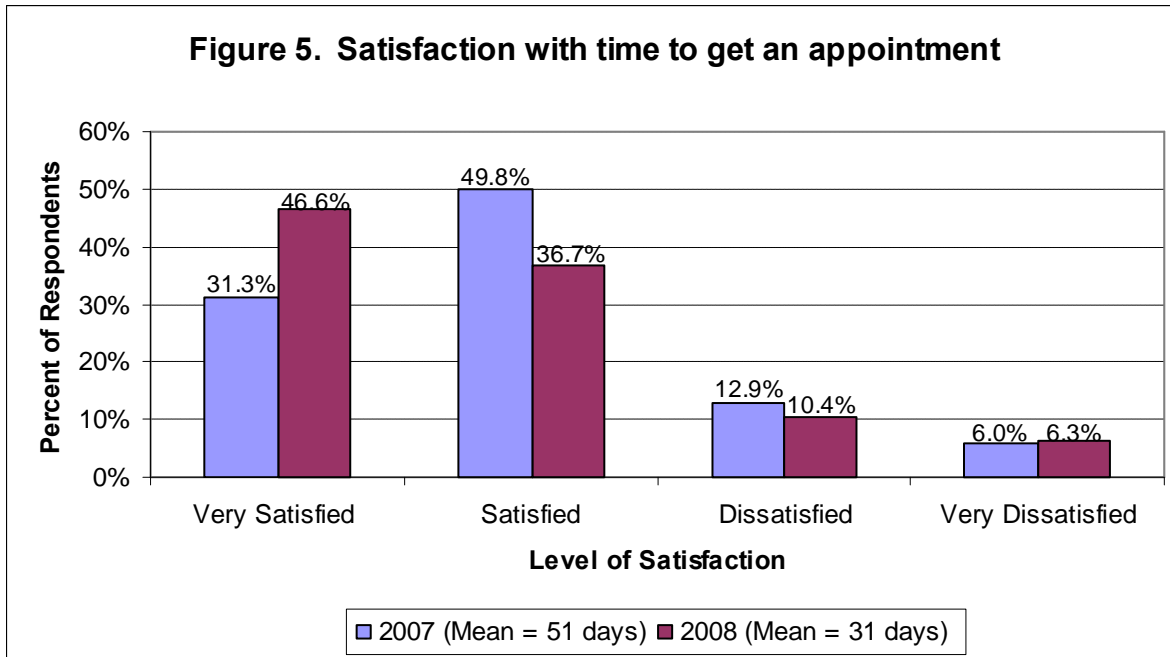


75% Received Appointment within 45 Days

Sixty-eight percent of respondents reported calling a CRS clinic for an appointment in the past 12 months (Q10). Of those, 75 percent (CI=69.3, 80.7) were able to get one within 45 days (Q11). This was significantly higher from 2007, where 63 percent were able to get an appointment at a CRS clinic within 45 days (see Figure 4). Survey results revealed better performance when compared to CRSA's Current Member Referral Performance Measure, where 51.1 percent of specialty clinic appointments occurred within 45 days for Quarter 1 of Fiscal Year 2008.



The majority (83.3%) reported being satisfied or very satisfied with how long it took to get their appointment. There were no statistically significant differences by site. The percentage of respondents who were very satisfied with the time to get an appointment was significantly higher in 2008 (46.6%) than in 2007 (31.3%, see Figure 5). The majority of very satisfied respondents (91%) received an appointment within 45 days or less. The average time that participants reported waiting to get an appointment at a CRS clinic was 31 days, with responses ranging from one day to 243 days. This was a significant improvement from the 2007 average of 51 days. Again, survey results revealed better performance when compared to CRSA's Current Member Referral Performance Measure, where the average time to get a specialty appointment was 63 days for Quarter 1 of Fiscal Year 2008.



88.5% Waited Less Than 45 Minutes Before Being Taken to Exam Room

During a CRS specialty clinic appointment, several specialists may see a patient in the same day. It is not uncommon for patients to spend an entire day at the clinic seeing multiple specialists and social workers. When respondents were asked to report their wait time before being taken to the exam room, 88.5 percent (CI=84.7, 92.2) reported that they usually waited 45 minutes or less (Q13). Differences in compliance rates between contractor sites were not statistically significant, nor were there significant differences from the 2007 rating.

MEMBER SERVICE AND TREATMENT

At CRS clinics, youth may not feel so conspicuously different because the staff are familiar with them and understand their conditions. CRS clinics are places where children and youth do not have to explain how they are different and their need for special accommodations.

Several survey items asked about the way that children and their families were treated by clinic staff (see Table 2). The vast majority (90%) of respondents said they were always treated with courtesy and respect (Q14), and 81.7 percent felt that the clinic staff were always as helpful

as they should be (Q15). Similarly high proportions are reported for the remaining customer service measures. Eighty-six percent said that CRS doctors or other health providers always showed respect for what they had to say (Q20), 83.6 percent said that CRS doctors and other providers always made it easy to discuss their questions and concerns (Q21), and 82 percent said that they always had their questions answered by their CRS providers (Q22).

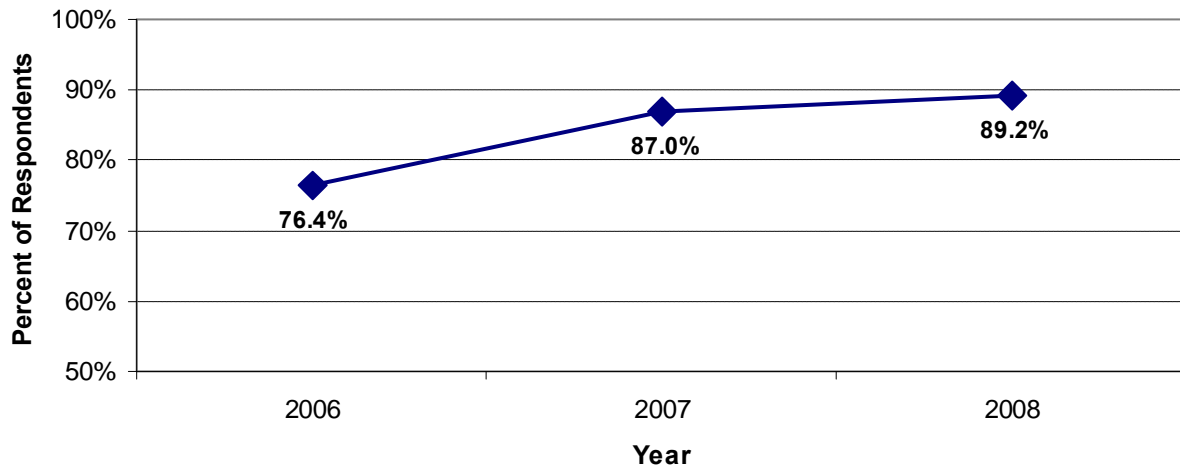
Table 2. Questions Related to Member Service

Question	2006	2007	2008
Q14. Staff always treated you and your child with courtesy and respect.	85%	87%	90%
Q15. Staff were always as helpful as you thought they should be.	75%	80%	82%
Q20. CRS doctors or other health providers always showed respect for what you had to say.	77%	84%	86%
Q21. CRS doctors or other health providers always made it easy for you to discuss your questions or concerns.	80%	80%	84%
Q22. You always had your questions answered by your child's CRS doctors or other health providers.	78%	80%	82%

It is widely accepted that having families of children with special health care needs involved in all levels of decision making is a best practice. Several questions were asked regarding the processes by which decisions about the child's health care were made. Under half of the respondents (53%, CI=47.2, 58.9) reported that decisions about their children's health care were made during CRS visits (Q24).

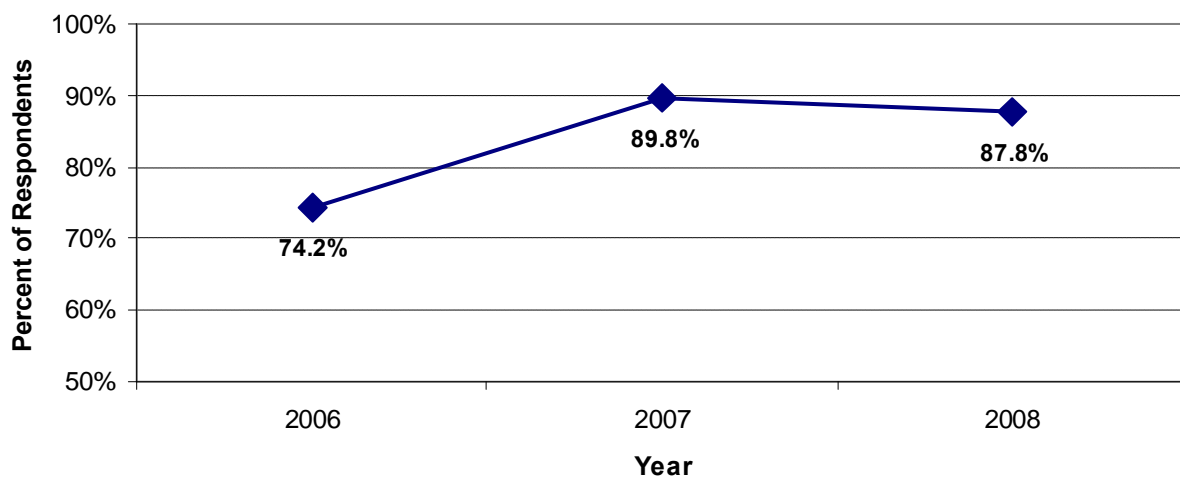
Over the past two years, family involvement in decision making has significantly increased. When decisions were made, the majority (89.2%) reported usually or always being offered choices about their child's health care (Q25). This was a significant improvement from the 76.4 percent reported in 2006 (see Figure 6).

Figure 6. Percentage of respondents who reported usually or always being offered choices about their child's health care when decisions were made (Q25)

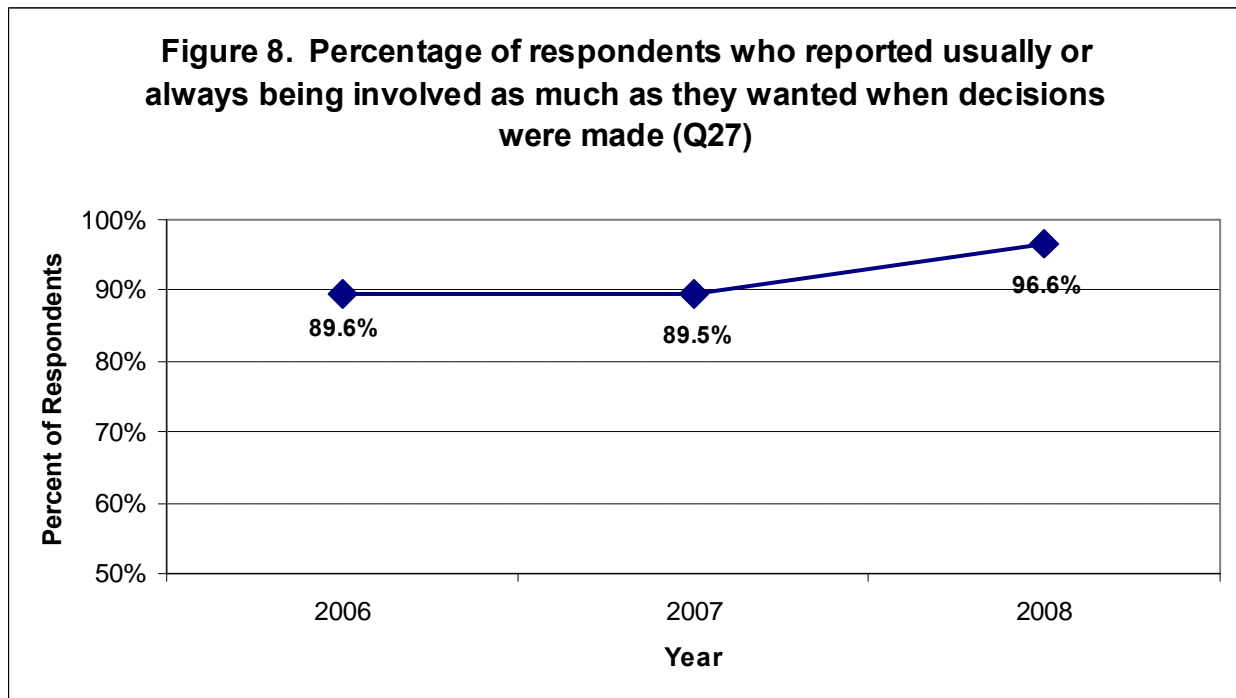


When decisions were made, 87.8 percent reported usually or always being asked to tell the health care provider what choice they prefer (Q26). This was significantly higher than the percentage reported in 2006 (74.2%, see Figure 7).

Figure 7. Percentage of respondents who reported usually or always being asked to tell their child's provider what choices they prefer when decisions were made (Q26)



Nearly all of the respondents (96.6%) said they were usually or always involved as much as they wanted when decisions were made (Q27) which was significantly higher than the reported 90 percent in 2007 (see Figure 8).



CULTURAL COMPETENCY

Communication between families and CRS clinic staff, including the need for translation services, are an important component of a culturally competent program. Families were asked about the need for and the delivery of translation services, as well as the clinic staff's ability to both listen carefully and explain things in a way that family members could understand regardless of language spoken. Nearly 80 percent of respondents reported that clinic staff always listened carefully to them (Q16), and a higher proportion (87.4%) reported that clinic staff always explained things to them in a way they could understand (Q19). Approximately 27 percent of respondents needed an interpreter within the last 12 months (Q29), and 93.2 percent always received translation services when they were requested (Q30).

Two questions from the Mental Health Statistics Improvement Program (MHSIP) Youth Services Survey were added in 2007 to further evaluate cultural competency. Respondents were asked to rate their level of agreement with the following statements:

- Q17 - Staff respected my family's religious/spiritual beliefs.
- Q18 - Staff were sensitive to my cultural/ethnic background.

Eighty percent agreed or strongly agreed that the staff respected their families' religious/spiritual beliefs (Q17). This was a statistically significant increase from 68 percent reported in 2007. Many of the respondents challenged the relevance of this question, claiming the topic of religiosity or spirituality "never came up." Eighteen percent of the respondents reported "neutral" which was lower than 29 percent reported in 2007. Less than two percent strongly disagreed with the statement.

Eighty-one percent agreed or strongly agreed that the staff was sensitive to their cultural/ethnic background (Q18). Again, this was a statistically significant increase from 73 percent reported in 2007. Respondents challenged the relevance of this question as well, and 17 percent of them answered with "neutral." However, this was lower than the percentage reported in 2007 (25%). Less than three percent reported disagreeing or strongly disagreeing with the statement.

The results to questions involving cultural competency were also evaluated by racial/ethnic group (see Appendix E). For most of the questions, there were no statistical differences found when the responses of White, Non-Hispanic families were compared to those of minorities or when responses of Hispanic families were compared to those of Non-Hispanic families. However, the responses from the two comparisons were significantly different for the two MHSIP questions:

- About 86 percent of minority families reported they agreed or strongly agreed that their religious/spiritual beliefs were respected by CRS staff (Q17) which was significantly higher than the percentage reported by White, Non-Hispanic families (64.3%). The proportion of Hispanic families (89.9%) who agreed or strongly agreed with the statement was significantly higher than of Non-Hispanic families (67.8%).
- More minority families (85.5%) reported they agreed or strongly agreed that CRS staff were sensitive to their cultural/ethnic background (Q18) than White Non-Hispanic families (67.1%). Almost 90 percent of Hispanic families agreed or strongly agreed with the statement which was significantly higher than 69.5 percent of Non-Hispanic families.
- When compared to 2007, the 2008 results showed a significant increase in Hispanic and minority families who agreed or strongly agreed that the CRS staff had respect for the family's religious/spiritual beliefs and were sensitive to the family's cultural/ethnic background.

Additionally, the responses of survey participants who needed an interpreter were compared to the responses of those who did not need an interpreter. No statistical differences between the groups existed for the questions related to cultural competency, except among the results of the two MHSIP questions:

- Ninety-six percent of respondents who needed an interpreter agreed or strongly agreed that staff respected their families' religious/spiritual beliefs (Q17) while only 74.5 percent of those who did not need an interpreter agreed or strongly agreed with the statement.
- More respondents who needed an interpreter (95.9%) reported that staff were sensitive to their cultural/ethnic background (Q18) than those who did not need an interpreter (75.5%).

DISCUSSION

For a third consecutive year, CRS families continue to characterize their child's overall health status favorably. Ninety percent of respondents reported that their children's health was excellent, very good, or good, despite their medical challenges. Overall, CRS care was rated at an average of 9.0 on a 10-point scale (with 10 being the highest level). Satisfaction levels remained high in 2008, indicating that families felt they were well-informed and were treated with courtesy and respect by CRS doctors and clinic staff. Additionally, results showed that family involvement in decision making significantly increased over the past two years.

Information was collected to evaluate compliance with AHCCCS standards for access to care for specialty services. The majority of respondents (88.5%) reported waiting times in the office were within standards (45 min). Seventy-five percent of respondents were able to obtain an appointment with a specialist within 45 days which was significantly higher than 63 percent reported in 2007. The average time of 31 days that participants reported waiting to get an appointment at a CRS clinic was a significant improvement from the 2007 average of 51 days.

Of the respondents who needed urgent care, about half were able to access urgent care within the AHCCCS standard of 72 hours (47.4%). Although this compliance rate was low, it was significantly higher than that reported in 2007 (32.2%). It is possible that this low compliance rate was in part a result of misinterpretation of the survey question. Survey respondents may not have interpreted "right away" to mean "urgent care." This possibility is supported by the results of a related question which asked how satisfied respondents were with how long it took to get care right away. In Q7, 89 percent of respondents reported that they were satisfied or very satisfied with how long it took to get care right away. The use of the term

urgent care or a further explanation of what kind of care is in question should be considered in future surveys.

A high proportion of wrong numbers was again a problem in the administration of this year's survey (31%). This poses a problem not only for survey purposes, but more importantly, for contacting patients about their health care. It is unknown whether wrong numbers resulted from the contractors' systematic lack of updating patient information, from patients intentionally withholding contact information, or members simply failing to update their records when contact information changes.

Fourteen percent of respondents required translation of the survey into Spanish and were easily accommodated by phone interviewers. Three respondents requested translation of the survey into another language, one for Arabic, one for Navajo, and one for Vietnamese. The surveys for the Arabic- and Navajo-speaking families were successfully completed using translation services. The Vietnamese-speaking family was not successfully contacted again, although translation services were available.

The majority of members in all ethnic groups reported high satisfaction levels in 2008. There was a significant increase in the percentage of respondents, especially among Hispanic and minority families, who agreed or strongly agreed that the CRS staff had respect for the family's religious/spiritual beliefs and were sensitive to the family's cultural/ethnic background. There were fewer neutral responses in 2008 than previously, which suggests that the topics may have been brought up and discussed more during clinic visits or that survey interviewers helped increase respondents' understanding of the questions. CRS strives to continue the increasing trend of positive feedback from families reporting that their beliefs were respected and that staff were culturally sensitive.

APPENDIX A: METHODOLOGY

Sample Selection

The sampling frame included all CRS members less than 21 years of age who were continuously enrolled in CRS and an AHCCCS Health Plan between January 1, 2007 and December 31, 2007. Members with a gap in enrollment of more than 30 days were excluded. The sampling frame included a total of 12,938 members. A sample size of 377 was calculated to tolerate no more than a 5% margin of error at a 95% confidence level, using the following formulas:

$$n = \frac{Nx}{((N-1)E^2 + x)}$$

$$x = z^2 p(1-p)$$

*N was rounded to 20,000 for use in the calculations

where N = number of members in the sampling frame (population)

n = minimum sample size,

z = the distance from the mean associated with confidence level (1.96 for a 95% confidence level),

E = margin of error (.05)

p = the estimated proportion expected to be associated with a given value of a variable (the most conservative assumption = 0.5 was used).

The Family Centered Survey response rate in 2007 was 49%; thus, a 50% response rate was anticipated for 2008. This resulted in 754 sampled members. The simple random sample was drawn using SPSS version 14.0.

Survey Administration

The survey tool is based primarily on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with modifications to accommodate the special population and program characteristics of CRS (see Appendix B). It also includes two questions from the Mental Health Statistics Improvement Program (MHSIP) Youth Services Survey to gather information on cultural competence. The tool was translated into Spanish to accommodate the high percentage of Spanish-speaking families in the CRS program. Three other translation requests were received by members, one for Arabic, one for Navajo, and one for Vietnamese. The surveys for the Arabic- and Navajo-speaking families were successfully completed using translation services. The Vietnamese-speaking family was not successfully contacted again, although translation services were available.

The survey was administered by four contracted phone interviewers and one OCSHCN staff member. Two interviewers were able to conduct interviews with Spanish-speaking respondents. The data entry tool was populated with members' contact information and key demographic variables. Interviewers were trained on the data entry tool, and its ability to accurately capture data was verified before survey implementation. In addition, training about the fundamental aspects of how CRS clinics operate was conducted. Some respondents who were reached by phone needed more information about the program or had complaints about their experiences with CRS. For these cases, the interviewer submitted a descriptive form to CRSA Member Services who either assisted the member or referred them to Quality Management for follow-up. Twenty-five complaints were referred to Quality Management, of which 19 were determined to be quality of care issues. Only four (21%) of these cases were substantiated.

Members were tracked using cards containing their contact information, as well as the date, time and result of each survey attempt. Cards were then organized according to the number of attempts made, need for translation, and the preferred time of day to call the member, when indicated. Up to 12 call attempts were made for each member. Calls were made between the hours of 10am and 6pm on weekdays and weekends. Survey administration began January 28th, and continued until March 17, 2008.

Analysis

Survey data was collected in MS Access and exported to SPSS 14.0 for analysis. Response rates and key outcomes were calculated by site. Within the body of this report, only valid responses are displayed (i.e., valid responses exclude those responses which were either not applicable or missing). Appendix C is a complete breakdown of statewide results including missing values, and Appendix D is a comparison of results by site.

Ninety-five percent confidence intervals were calculated for point estimates using SPSS and the following formula:

$$p \pm z * \sqrt{p(1-p)/n}$$

where p = the calculated proportion of a given variable

z = the distance from the mean associated with confidence level (1.96 for a 95% confidence level)

n = the number of respondents

When findings were presented as statistically significant, differences in proportions or means were tested at $p < 0.05$.

Results

Of the 754 CRS members selected, 416 were successfully contacted, giving an initial response rate of 55%. Thirty-six respondents stated that they were no longer CRS members, decreasing the total eligible sample to 718. Accounting for refusals to complete the survey and updated eligibility status, 327 surveys were completed, giving an adjusted response rate of 46%. Response rates at the site level varied from a low of 31.4% to a high of 60.9% and were similar to last year's rates. The site-level response rates were not significantly different from those in 2007. Nearly one-third (31%) of sampled members could not be reached due to wrong or disconnected numbers.

Table A1: Family Centered Survey Response Rates by Site, n=718

CRS Regional Clinic Site	Number of Sampled Members*	Number of Survey Respondents	Response Rate
Phoenix	419	200	47.7%
Tucson	187	85	45.5%
Flagstaff	86	27	31.4%
Yuma	23	14	60.9%

*The site was unknown for three of the sampled members.

Demographic Characteristics of Respondents vs. Population

The mean age of children represented by respondents was 9.2 years, with nearly 64% of children between the ages of 4 and 14; 51% were male, and 58% were of Hispanic or Latino descent. Most of the members (55%) spoke English as their main language at home, with an additional 12% speaking mainly Spanish at home. Twenty-four percent of members spoke both English and Spanish. The most common diagnostic conditions related to nervous system (28.7%), circulatory system (20.5%), and musculoskeletal/connective tissue disorders (16.8%).

Without a census, it is possible that the members who completed the survey had different opinions than the CRS population as a whole. This would imply that estimates from the survey data were inaccurate, or *biased*. One way to evaluate the potential for bias is to compare respondents to the original sampling population on known characteristics, such as age, sex,

ethnicity, and enrolling diagnosis. Race data was not used as data from the CRS system was inadequate to allow for a comparison, with over 80% of respondents having an "unknown" race.

Respondents were similar to the population in terms of age, sex, and most enrolling diagnoses. However, there was a statistically significant difference between the proportion of Hispanic respondents and the proportion of Hispanic members in the population. Fifty-eight percent of survey respondents were Hispanic, while only 47% of the CRS population was identified as such by CRSA administrative data. The survey data show that more Hispanics rated their CRS health care higher than Non-Hispanics. It is possible that satisfaction levels are over-estimated because of Hispanics being represented in higher proportions. Other differences in results related to ethnicity are addressed within the body of the report and in Appendix E.

Table A2: Demographic Characteristics of Respondents vs. CRS population

Characteristic	Respondents (n=327)		Population (N=12,938)	
	n	%	n	%
Age ó Mean (95% CI)	9.2 (8.6 -9.8)		9.4 (9.3-9.5)	
< 1	1	0.3	40	0.3
1-3	55	16.8	2175	16.8
4-9	123	37.6	4751	36.7
10-14	86	26.3	3060	23.7
15-17	37	11.3	1756	13.6
18-21	25	7.6	1156	8.9
Sex				
Male	166	50.8	6982	54.0
Female	161	49.2	5956	46.0
Ethnicity				
Hispanic/Latino descent*	188	58.2	6046	46.7
Not Hispanic/Latino	135	41.8	6892	53.3
Disease Class				
Blood & Blood Forming Organs	1	0.3	68	0.5
Circulatory System	67	20.5	2755	21.3
Congenital Anomalies	4	1.2	175	1.4
Digestive System	31	9.5	871	6.7
Endocrine, Nutritional, Metabolic	18	5.5	477	3.7
Genitourinary System*	8	2.4	501	3.9
Musculoskeletal/Connective*	55	16.8	2245	17.4
Neoplasm	7	2.1	289	2.2
Nervous System*	94	28.7	3460	26.7
Other	10	3.1	338	2.6
Respiratory System	1	0.3	58	0.4
Sense Organs	30	9.2	1665	12.9
Skin & Subcutaneous Tissue	1	0.3	36	0.3

*Respondents are significantly different from Population

APPENDIX B: FAMILY CENTERED SURVEY, 2008

Family Centered Survey

All information that would let someone identify you or your family will be kept private. The Arizona Department of Health Services, Office for Children with Special Health Care Needs will not share your personal information with anyone without your OK. You may choose to answer this survey or not. If you choose not to, this will not affect the benefits your child receives.

If you want to know more about this survey, please call Thara MacLaren at (602) 542-2881.

Name of the child: _____ Gender of child

Qualifying Condition: _____

Parent/guardian Name: _____

Phone number: _____

- ☐ Phone disconnected
- ☐ No answer, **RECORD DATE, TIME AND OUTCOME**
- ☐ Phone answered

Hello, this is (INTERVIEWER NAME) _____ calling from Arizona Department of Health Services. We'd like to talk with you about your experiences with the Children's Rehabilitative Services Program. Your answers will help us to make the program better. May I please speak to (Parent/Guardian name) _____?

- ☐ If person is parent/guardian, **GO TO CONSENT**
- ☐ No one by that name at this phone number, **RECORD DATE, TIME AND OUTCOME**
- ☐ Not available

We need to talk with the parent or guardian who lives in this household who knows the most about the health care that (child's name) _____ receives through CRS.

Would that be you?

- ☐ Yes, **GO TO SURVEY INTRODUCTION**
- ☐ No

Who would that be? _____ . Is he/she available?

- ☐ Yes **GO TO SURVEY INTRODUCTION**
- ☐ No, **GO TO CALL BACK**

CALL BACK:

- ☐ AM _____
- ☐ PM _____
- ☐ Weekends _____
- ☐ Need Spanish speaker
- ☐ Other language _____

SURVEY INTRODUCTION

We are conducting a satisfaction survey of families who receive health care services through Children's Rehabilitative Services (CRS). Your family has been selected at random to be included in the study. Your answers will help us to make the program better.

You may choose to do this interview or not. If you do, your responses will be kept private. Your decision to do the interview will not affect any benefits you get. The questions should take about 15 minutes to answer.

Do you wish to participate in this survey?

- ☐ **Parent/guardian agrees**
- ☐ **Parent/guardian refuses, Thank them for their time and say good-bye.**

IF THE FAMILY MEMBER DOES NOT HAVE TIME TO PARTICIPATE IN THE INTERVIEW NOW, GO TO CALL BACK.

I'd like to begin the interview now, but before we begin, do you have any questions about the survey?

If the parent or guardian has additional questions or concerns have them call Heather Dunn at (602) 364-2286.

Our records show that your child (_____) is now in CRS. Is that right?

- ¹☐ Yes
- ⁰☐ No, Thank them for their time

1. In the last 12 months, did your child see a CRS specialty doctor?
 - ¹ ☐ Yes → If Yes, Go to Question 3
 - ⁰ ☐ No → If No, Skip Question 4

2. In the past 12 months, did you try to get an appointment with a CRS specialty doctor?
 - ¹ ☐ Yes
 - ⁰ ☐ No → If No, Go to Question 5

3. In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see?
 - ¹ ☐ A big problem
 - ² ☐ A small problem
 - ³ ☐ Not a problem

4. We want to know your rating of the CRS specialty doctor your child saw most often in the last 12 months. Using any number from 0 to 10, where 0 is the worst specialist possible, and 10 is the best specialist possible, what number would you use to rate your child's specialty doctor?
 - ⁰ ☐ 0 Worst specialist possible
 - ¹ ☐ 1
 - ² ☐ 2
 - ³ ☐ 3
 - ⁴ ☐ 4
 - ⁵ ☐ 5
 - ⁶ ☐ 6
 - ⁷ ☐ 7
 - ⁸ ☐ 8
 - ⁹ ☐ 9
 - ¹⁰ ☐ 10 Best specialist possible

5. In the last 12 months, did you call the CRS clinic during regular clinic hours to get help or advice for your child?
 - ¹ ☐ Yes
 - ² ☐ No → If No, Go to Question 7

6. In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child?
 - ¹ ☐ Never
 - ² ☐ Sometimes
 - ³ ☐ Usually
 - ⁴ ☐ Always

7. In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care at a CRS clinic?
 - ¹ ☐ Very satisfied
 - ² ☐ Satisfied
 - ³ ☐ Dissatisfied
 - ⁴ ☐ Very dissatisfied
 - ⁵ ☐ My child did not need urgent care → Go to Question 9

8. In the last 12 months, when your child needed care right away for their CRS condition, most of the time, how long did you have to wait to get care at a CRS clinic?
 - ☐ _____ days
 - ☐ _____ weeks
 - ☐ _____ months
 - ☐ I could not get an appointment

9. In the last 12 months, how many times did your child go to an emergency room for their CRS condition?

⁰☐ None
¹☐ 1
²☐ 2
³☐ 3
⁴☐ 4
⁵☐ 5 to 9
⁶☐ 10 or more

10. In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic?

¹☐ Very satisfied
²☐ Satisfied
³☐ Dissatisfied
⁴☐ Very dissatisfied
⁵☐ I did not try to get an appointment → Go to Question 12

11. In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment?

☐ _____ days
☐ _____ weeks
☐ _____ months
☐ I could not get an appointment

12. In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?

⁰☐ None → Go to Question 30
¹☐ 1
²☐ 2
³☐ 3
⁴☐ 4
⁵☐ 5 to 9
⁶☐ 10 or more

13. In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room?

¹☐ Less than 15 minutes
²☐ 15 . 30 minutes
³☐ 31 . 45 minutes
⁴☐ 46 . 60 minutes
⁵☐ More than an hour

14. In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?

¹☐ Never
²☐ Sometimes
³☐ Usually
⁴☐ Always

15. In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?

- ¹☐ Never
- ²☐ Sometimes
- ³☐ Usually
- ⁴☐ Always

16. In the last 12 months, how often did the CRS clinic staff listen carefully to you?

- ¹☐ Never
- ²☐ Sometimes
- ³☐ Usually
- ⁴☐ Always

17. Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.

- ¹☐ Strongly Disagree
- ²☐ Disagree
- ³☐ Neutral
- ⁴☐ Agree
- ⁵☐ Strongly Agree

18. Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background.

- ¹☐ Strongly Disagree
- ²☐ Disagree
- ³☐ Neutral
- ⁴☐ Agree
- ⁵☐ Strongly Agree

19. In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?

- ¹☐ Never
- ²☐ Sometimes
- ³☐ Usually
- ⁴☐ Always

20. In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?

- ¹☐ Never
- ²☐ Sometimes
- ³☐ Usually
- ⁴☐ Always

21. In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?

- ¹☐ Never
 - ²☐ Sometimes
 - ³☐ Usually
 - ⁴☐ Always
 - ⁵☐ I didn't have any questions →
- Go to Question 22**

22. In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?

- ¹☐ Never
- ²☐ Sometimes
- ³☐ Usually
- ⁴☐ Always

23. In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?

¹☐ Never
²☐ Sometimes
³☐ Usually
⁴☐ Always
⁵☐ I didn't need any information

24. In the last 12 months, were any decisions about your child's health care made during your CRS visits?

¹☐ Yes
⁰☐ No → If No, Go to Question 27

25. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?

¹☐ Never
²☐ Sometimes
³☐ Usually
⁴☐ Always

26. When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?

¹☐ Never
²☐ Sometimes
³☐ Usually
⁴☐ Always

27. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted?

¹☐ Never
²☐ Sometimes
³☐ Usually
⁴☐ Always

28. Using any number from 0 to 10, where 0 is the worst health care possible, and 10 is the best health care possible, what number would you use to rate all your child's CRS health care in the last 12 months?

⁰☐ 0 Worst health care possible
¹☐ 1
²☐ 2
³☐ 3
⁴☐ 4
⁵☐ 5
⁶☐ 6
⁷☐ 7
⁸☐ 8
⁹☐ 9
¹⁰☐ 10 Best health care possible

29. An interpreter is someone who repeats or signs what one person says in a language used by another person.

In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?

¹☐ Yes
⁰☐ No → If No, Go to Question 31

30. In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?

- ¹☐ Never
- ²☐ Sometimes
- ³☐ Usually
- ⁴☐ Always

31. In general, how would you rate your child's overall health now?

- ¹☐ Excellent
- ²☐ Very Good
- ³☐ Good
- ⁴☐ Fair
- ⁵☐ Poor

32. Is your child of Hispanic or Latino origin or descent?

- ¹☐ Yes, Hispanic or Latino
- ⁰☐ No, Not Hispanic or Latino

33. What is your child's race? Please mark one or more.

- ¹☐ White
- ²☐ Black or African-American
- ³☐ Asian
- ⁴☐ Native Hawaiian or other Pacific Islander
- ⁵☐ American Indian or Alaska Native
- ⁶☐ Other

34. What is the highest grade or level of school that you have completed?

- ¹☐ 8th grade or less
- ²☐ Some high school, but did not graduate
- ³☐ High school graduate or GED
- ⁴☐ Some college or 2-year degree
- ⁵☐ 4-year college graduate
- ⁶☐ More than 4-year college degree

35. What language do you mainly speak at home?

- ¹☐ English
 - ²☐ Spanish
 - ³☐ Some other language
(please print)
-

36. What language does your child mainly speak at home?

- ¹☐ English
 - ²☐ Spanish
 - ³☐ Some other language
(please print)
-

37. How are you related to the child?

- ¹☐ Mother or father
 - ²☐ Grandparent
 - ³☐ Aunt or uncle
 - ⁴☐ Older brother or sister
 - ⁵☐ Other relative
 - ⁶☐ Legal guardian
 - ⁷☐ Self
 - ⁸☐ Someone else *(please print)*
-

Thank you for completing this survey

APPENDIX C: SURVEY RESPONSES, STATEWIDE

1. In the last 12 months, did your child see a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	59	18.0	18.0	18.0
	Yes	268	82.0	82.0	100.0
	Total	327	100.0	100.0	

2. In the past 12 months, did you try to get an appointment with a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	46	78.0	82.1	82.1
	Yes	10	16.9	17.9	100.0
	Total	56	94.9	100.0	
Missing	System	3	5.1		
Total		59	100.0		

3. In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A big problem	29	8.9	10.5	10.5
	A small problem	21	6.4	7.6	18.1
	Not a problem	227	69.4	81.9	100.0
	Total	277	84.7	100.0	
Missing	System	50	15.3		
Total		327	100.0		

4. Using any number from 0 to 10, where 0 is the worst specialist possible, and 10 is the best specialist possible, what number would you use to rate your child's specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	4	1.5	1.5	1.5
	4 to 7	18	6.7	6.7	8.2
	8 to 10	246	91.8	91.8	100.0
	Total	268	100.0	100.0	

Mean = 9.18, Standard Deviation = 1.509

5. In the last 12 months, did you call the CRS clinic during regular clinic hours to get help or advice for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	182	55.7	56.3	56.3
	Yes	141	43.1	43.7	100.0
	Total	323	98.8	100.0	
Missing	System	4	1.2		
Total		327	100.0		

6. In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	8	5.7	5.7	5.7
	Sometimes	21	14.9	14.9	20.6
	Usually	17	12.1	12.1	32.6
	Always	95	67.4	67.4	100.0
	Total	141	100.0	100.0	

7. In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	66	20.2	48.5	48.5
	Satisfied	55	16.8	40.4	89.0
	Dissatisfied	9	2.8	6.6	95.6
	Very Dissatisfied	6	1.8	4.4	100.0
	Total	136	41.6	100.0	
Missing	My child did not need urgent care	189	57.8		
	System	2	.6		
	Total	191	58.4		
Total		327	100.0		

8. In the last 12 months, when your child needed care right away for their CRS condition, most of the time, how long did you have to wait to get care at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Within 3 Days	63	46.3	47.4	47.4
	4-7 days	14	10.3	10.5	57.9
	More than 7 days	51	37.5	38.3	96.2
	Could not get an appointment	5	3.7	3.8	100.0
	Total	133	97.8	100.0	
Missing	System	3	2.2		
Total		136	100.0		

Mean = 30.66 days, Standard Deviation = 55.31 days

9. In the last 12 months, how many times did your child go to an emergency room for their CRS condition?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	256	78.3	78.3	78.3
	1	30	9.2	9.2	87.5
	2	21	6.4	6.4	93.9
	3	4	1.2	1.2	95.1
	4	7	2.1	2.1	97.2
	5 to 9	5	1.5	1.5	98.8
	10 or more	4	1.2	1.2	100.0
	Total	327	100.0	100.0	

10. In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	103	31.5	46.6	46.6
	Satisfied	81	24.8	36.7	83.3
	Dissatisfied	23	7.0	10.4	93.7
	Very Dissatisfied	14	4.3	6.3	100.0
	Total	221	67.6	100.0	
Missing	I did not try to get an appointment	106	32.4		
Total		327	100.0		

11. In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	45 Days or less	165	74.7	75.0	75.0
	46 to 90 days	15	6.8	6.8	81.8
	More than 90 days	28	12.7	12.7	94.5
	Could not get an appointment	12	5.4	5.5	100.0
	Total	220	99.5	100.0	
Missing	System	1	.5		
Total		221	100.0		

Mean = 31.07 days, Standard Deviation = 49.56 days

12. In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	46	14.1	14.2	14.2
	1	65	19.9	20.0	34.2
	2	59	18.0	18.2	52.3
	3	39	11.9	12.0	64.3
	4	37	11.3	11.4	75.7
	5 to 9	53	16.2	16.3	92.0
	10 or more	26	8.0	8.0	100.0
	Total	325	99.4	100.0	
Missing	System	2	.6		
Total		327	100.0		

13. In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 15 minutes	109	39.1	39.2	39.2
	15-30 minutes	117	41.9	42.1	81.3
	31-45 minutes	20	7.2	7.2	88.5
	46-60 minutes	12	4.3	4.3	92.8
	More than an hour	20	7.2	7.2	100.0
	Total	278	99.6	100.0	
Missing	System	1	.4		
Total		279	100.0		

14. In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	1.1	1.1	1.1
	Sometimes	11	3.9	4.0	5.1
	Usually	13	4.7	4.7	9.7
	Always	250	89.6	90.3	100.0
	Total	277	99.3	100.0	
Missing	System	2	.7		
Total		279	100.0		

15. In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	.7	.7	.7
	Sometimes	19	6.8	6.8	7.6
	Usually	30	10.8	10.8	18.3
	Always	227	81.4	81.7	100.0
	Total	278	99.6	100.0	
Missing	System	1	.4		
Total		279	100.0		

16. In the last 12 months, how often did the CRS clinic staff listen carefully to you?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	1.1	1.1	1.1
	Sometimes	18	6.5	6.5	7.6
	Usually	35	12.5	12.7	20.3
	Always	220	78.9	79.7	100.0
	Total	276	98.9	100.0	
Missing	System	3	1.1		
Total		279	100.0		

17. Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	4	1.4	1.4	1.4
	Neutral	51	18.3	18.3	19.8
	Agree	70	25.1	25.2	45.0
	Strongly Agree	153	54.8	55.0	100.0
	Total	278	99.6	100.0	
Missing	System	1	.4		
Total		279	100.0		

18. Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	5	1.8	1.8	1.8
	Disagree	2	.7	.7	2.5
	Neutral	46	16.5	16.5	19.1
	Agree	78	28.0	28.1	47.1
	Strongly Agree	147	52.7	52.9	100.0
	Total	278	99.6	100.0	
Missing	System	1	.4		
Total		279	100.0		

19. In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	.7	.7	.7
	Sometimes	13	4.7	4.7	5.4
	Usually	20	7.2	7.2	12.6
	Always	243	87.1	87.4	100.0
	Total	278	99.6	100.0	
Missing	System	1	.4		
Total		279	100.0		

20. In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	1	.4	.4	.4
	Sometimes	16	5.7	5.8	6.1
	Usually	21	7.5	7.6	13.7
	Always	239	85.7	86.3	100.0
	Total	277	99.3	100.0	
Missing	System	2	.7		
Total		279	100.0		

21. In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	.7	.8	.8
	Sometimes	16	5.7	6.6	7.4
	Usually	22	7.9	9.0	16.4
	Always	204	73.1	83.6	100.0
	Total	244	87.5	100.0	
Missing	I didn't have any questions	33	11.8		
	System	2	.7		
	Total	35	12.5		
Total		279	100.0		

22. In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	1.6	1.6	1.6
	Sometimes	17	7.0	7.0	8.6
	Usually	23	9.4	9.4	18.0
	Always	200	82.0	82.0	100.0
	Total	244	100.0	100.0	

23. In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	1.4	1.7	1.7
	Sometimes	15	5.4	6.6	8.3
	Usually	27	9.7	11.8	20.1
	Always	183	65.6	79.9	100.0
	Total	229	82.1	100.0	
Missing	I didn't need any information	48	17.2		
	System	2	.7		
	Total	50	17.9		
Total		279	100.0		

24. In the last 12 months, were any decisions about your child's health care made during your CRS visits?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	131	47.0	47.0	47.0
	Yes	148	53.0	53.0	100.0
	Total	279	100.0	100.0	

25. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	2.7	2.7	2.7
	Sometimes	12	8.1	8.1	10.8
	Usually	17	11.5	11.5	22.3
	Always	115	77.7	77.7	100.0
	Total	148	100.0	100.0	

26. When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	5	3.4	3.4	3.4
	Sometimes	13	8.8	8.8	12.2
	Usually	12	8.1	8.2	20.4
	Always	117	79.1	79.6	100.0
	Total	147	99.3	100.0	
Missing	System	1	.7		
Total		148	100.0		

27. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sometimes	5	3.4	3.4	3.4
	Usually	14	9.5	9.5	12.9
	Always	128	86.5	87.1	100.0
	Total	147	99.3	100.0	
Missing	System	1	1.1		
Total		148	100.0		

28. What number would you use to rate your child's CRS care in the last 12 months?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	6	2.2	2.2	2.2
	4 to 7	27	9.7	9.7	11.8
	8 to 10	246	88.2	88.2	100.0
	Total	279	100.0	100.0	

Mean = 9.04, Standard Deviation = 1.71

29. In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	205	73.5	73.5	73.5
	Yes	74	26.5	26.5	100.0
	Total	279	100.0	100.0	

30. In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sometimes	4	5.4	5.4	5.4
	Usually	1	1.4	1.4	6.8
	Always	69	93.2	93.2	100.0
	Total	74	100.0	100.0	

31. In general, how would you rate your child's overall health now?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Excellent	90	27.5	27.7	27.7
	Very Good	114	34.9	35.1	62.8
	Good	87	26.6	26.8	89.5
	Fair	31	9.5	9.5	99.1
	Poor	3	.9	.9	100.0
	Total	325	99.4	100.0	
Missing	System	2	.6		
Total		327	100.0		

32. Is your child of Hispanic or Latino origin or descent?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	135	41.3	41.5	41.8
	Yes	188	57.5	57.8	100.0
	Total	323	99.4	100.0	
Missing	System	4	1.2		
Total		327	100.0		

33. What is your child's race?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	White	91	27.8	29.5	29.5
	Black	11	3.4	3.6	33.1
	Asian	4	1.2	1.3	34.4
	American Indian	29	8.9	9.4	43.8
	Other	169	51.7	54.9	98.7
	Multi-racial	4	1.2	1.3	100.0
	Total	308	94.2	100.0	
Missing	Refused	19	5.8		
Total		327	100.0		

34. What is the highest grade or level of school that you have completed?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	8th Grade or less	30	9.2	9.2	9.2
	Some high school, but did not graduate	61	18.7	18.8	28.0
	High school graduate or GED	103	31.5	31.7	59.7
	Some college or 2-year degree	98	30.0	30.2	89.8
	4-year college graduate	15	4.6	4.6	94.5
	More than 4-year college degree	18	5.5	5.5	100.0
	Total	325	99.4	100.0	
Missing	System	2	.6		
Total		327	100.0		

35. What language do you mainly speak at home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	180	55.0	55.4	55.4
	Spanish	102	31.2	31.4	86.8
	English & Spanish	34	10.4	10.5	97.2
	Nonverbal	1	.3	.3	97.5
	Other	6	1.8	1.8	99.4
	Arabic	1	.3	.3	99.7
	Navajo	1	.3	.3	100.0
	Total	325	99.4	100.0	
Missing	System	2	.6		
Total		327	100.0		

36. What language does your child mainly speak at home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	180	55.0	55.4	55.4
	Spanish	38	11.6	11.7	67.1
	English & Spanish	77	23.5	23.7	90.8
	Sign Language	4	1.2	1.2	92.0
	Nonverbal	7	2.1	2.2	94.2
	Not Speaking Yet	11	3.4	3.4	97.5
	Other	6	1.8	1.8	99.4
	Arabic	1	.3	.3	99.7
	Navajo	1	.3	.3	100.0
	Total	325	99.4	100.0	
Missing	System	2	.6		
Total		327	100.0		

37. How are you related to the child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mother or father	295	90.2	90.5	90.5
	Grandparent	20	6.1	6.1	96.6
	Aunt or uncle	1	.3	.3	96.9
	Older brother or sister	1	.3	.3	97.2
	Legal guardian	4	1.2	1.2	98.5
	Self	3	.9	.9	99.4
	Someone else	2	.6	.6	100.0
	Total	326	99.7	100.0	
Missing	System	1	.3		
Total		327	100.0		

APPENDIX D: SURVEY RESPONSES BY SITE

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
1.	In the last 12 months, did your child see a CRS specialty doctor? Yes No	164 36	(82.0) (18.0)	67 18	(78.8) (21.2)	24 3	(88.9) (11.1)	12 2	(85.7) (14.3)	267 59	(81.9) (18.1)
2.	In the past 12 months, did you try to get an appointment with a CRS specialty doctor? Yes No	4 29	(12.1) (87.9)	5 13	(27.8) (72.2)	1 2	(33.3) (66.7)	0 2	(0.0) (100.0)	10 46	(17.9) (82.1)
3.	In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see? A big problem A small problem Not a problem	21 14 132	(12.6) (8.4) (79.0)	6 4 62	(8.3) (5.6) (86.1)	1 2 22	(4.0) (8.0) (88.0)	1 1 10	(8.3) (8.3) (83.3)	29 21 226	(10.5) (7.6) (81.9)
4.	What number would you use to rate your child's specialty doctor? Mean ± sd 0 - 3 4 - 7 8 - 10	9.1±1.7 4 9 151	 (2.4) (5.5) (92.1)	9.4±1.1 0 4 63	 (0.0) (6.0) (94.0)	8.8±1.4 0 5 19	 (4.3) (20.8) (79.2)	9.4±0.8 0 0 12	 (0.0) (0.0) (100.0)	9.2±1.5 4 18 245	 (1.5) (6.7) (91.8)
5.	Did you call the CRS clinic during regular clinic hours to get help or advice for your child? Yes No	81 116	(41.1) (58.9)	38 46	(45.2) (54.8)	15 12	(55.6) (44.4)	7 7	(50.0) (50.0)	141 181	(43.8) (56.2)
6.	How often did you get the help or advice you needed for your child? Never Sometimes Usually Always	6 16 8 51	(7.4) (19.8) (9.9) (63.0)	1 3 7 27	(2.6) (7.9) (18.4) (71.1)	1 1 2 11	(6.7) (6.7) (13.3) (73.3)	0 1 0 6	(0.0) (14.3) (0.0) (85.7)	8 21 17 95	(5.7) (14.9) (12.1) (67.4)
7.	When your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care at a CRS clinic? Very Satisfied Satisfied Dissatisfied Very Dissatisfied	34 37 8 4	(41.0) (44.6) (9.6) (4.8)	24 15 1 1	(58.5) (36.6) (2.4) (2.4)	6 3 0 1	(60.0) (30.0) (0.0) (10.0)	2 0 0 0	(100.0) (0.0) (0.0) (0.0)	66 55 9 6	(48.5) (40.4) (6.6) (4.4)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
8.	When your child needed care right away for their CRS condition, how long did you have to wait to get care at a CRS clinic? Within 3 days 4 - 7 days More than 7 days	36	(46.2)	21	(55.3)	6	(60.0)	0	(0.0)	63	(49.2)
		8	(10.3)	4	(10.5)	1	(10.0)	1	(50.0)	14	(10.9)
		34	(43.6)	13	(34.2)	3	(30.0)	1	(50.0)	51	(39.8)
9.	In the last 12 months, how many times did your child go to an emergency room for their CRS condition? None 1 2 3 4 5 to 9 10 or more	149	(74.5)	71	(83.5)	22	(81.5)	13	(92.9)	255	(78.2)
		21	(10.5)	6	(7.1)	2	(7.4)	1	(7.1)	30	(9.2)
		13	(6.5)	5	(5.9)	3	(11.1)	0	(0.0)	21	(6.4)
		4	(2.0)	0	(0.0)	0	(0.0)	0	(0.0)	4	(1.2)
		6	(3.0)	1	(1.2)	0	(0.0)	0	(0.0)	7	(2.1)
		4	(2.0)	1	(1.2)	0	(0.0)	0	(0.0)	5	(1.5)
		3	(1.5)	1	(1.2)	0	(0.0)	0	(0.0)	4	(1.2)
10.	How satisfied were you with how long it took to get an appointment at a CRS clinic? Very Satisfied Satisfied Dissatisfied Very Dissatisfied	55	(44.0)	28	(43.8)	14	(63.6)	6	(60.0)	103	(46.6)
		45	(36.0)	25	(39.1)	8	(36.4)	3	(30.0)	81	(36.7)
		16	(12.8)	7	(10.9)	0	(0.0)	0	(0.0)	23	(10.4)
		9	(7.2)	4	(6.3)	0	(0.0)	1	(10.0)	14	(6.3)
11.	When you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment? 45 days or less 46 to 90 days More than 90 days	86	(73.5)	54	(90.0)	17	(81.0)	8	(80.0)	165	(79.3)
		12	(10.3)	2	(3.3)	0	(0.0)	1	(10.0)	15	(7.2)
		19	(16.2)	4	(6.7)	4	(19.0)	1	(10.0)	28	(13.5)
12.	Not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic? None 1 2 3 4 5 to 9 10 or more	30	(15.2)	13	(15.3)	1	(3.7)	2	(14.3)	46	(14.2)
		36	(18.2)	19	(22.4)	7	(25.9)	2	(14.3)	64	(19.8)
		38	(19.2)	10	(11.8)	9	(33.3)	2	(14.3)	59	(18.2)
		26	(13.1)	6	(7.1)	4	(14.8)	3	(21.4)	39	(12.0)
		23	(11.6)	10	(11.8)	1	(3.7)	3	(21.4)	37	(11.4)
		30	(15.2)	18	(21.2)	3	(11.1)	2	(14.3)	53	(16.4)
		15	(7.6)	9	(10.6)	2	(7.4)	0	(0.0)	26	(8.0)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
13.	In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room? Less than 15 minutes 15-30 minutes 31-45 minutes 46-60 minutes More than an hour	59	(35.1)	36	(50.7)	11	(42.3)	2	(16.7)	108	(39.0)
		74	(44.0)	27	(38.0)	9	(34.6)	7	(58.3)	117	(42.2)
		11	(6.5)	6	(8.5)	2	(7.7)	1	(8.3)	20	(7.2)
		8	(4.8)	1	(1.4)	2	(7.7)	1	(8.3)	12	(4.3)
		16	(9.5)	1	(1.4)	2	(7.7)	1	(8.3)	20	(7.2)
14.	How often did office staff at your child's CRS clinic treat you and your child with courtesy and respect? Never Sometimes Usually Always	2	(1.2)	1	(1.4)	0	(0.0)	0	(0.0)	3	(1.1)
		8	(4.8)	2	(2.8)	1	(3.8)	0	(0.0)	11	(4.0)
		10	(6.0)	2	(2.8)	0	(0.0)	1	(8.3)	13	(4.7)
		147	(88.0)	66	(93.0)	25	(96.2)	11	(91.7)	249	(90.2)
15.	How often were office staff at your child's CRS clinic as helpful as you thought they should be? Never Sometimes Usually Always	1	(0.6)	1	(1.4)	0	(0.0)	0	(0.0)	2	(0.7)
		16	(9.5)	0	(0.0)	1	(3.8)	2	(16.7)	19	(6.9)
		17	(10.1)	9	(12.7)	2	(7.7)	2	(16.7)	30	(10.8)
		134	(79.8)	61	(85.9)	23	(88.5)	8	(66.7)	226	(81.6)
16.	How often did the CRS clinic staff listen carefully to you? Never Sometimes Usually Always	1	(0.6)	1	(1.4)	1	(3.8)	0	(0.0)	3	(1.1)
		13	(7.8)	2	(2.8)	2	(7.7)	1	(8.3)	18	(6.5)
		21	(12.7)	8	(11.3)	4	(15.4)	2	(16.7)	35	(12.7)
		131	(78.9)	60	(84.5)	19	(73.1)	9	(75.0)	219	(79.6)
17.	Staff respected my family's religious/spiritual beliefs. Strongly Disagree Disagree Neutral Agree Strongly Agree	2	(1.2)	1	(1.4)	1	(3.8)	0	(0.0)	4	(1.4)
		0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)
		28	(16.7)	14	(19.7)	8	(30.8)	1	(8.3)	51	(18.4)
		41	(24.4)	20	(28.2)	6	(23.1)	3	(25.0)	70	(25.3)
		97	(57.7)	36	(50.7)	11	(42.3)	8	(66.7)	152	(54.9)
18.	Staff were sensitive to my cultural/ethnic background. Strongly Disagree Disagree Neutral Agree Strongly Agree	2	(1.2)	2	(2.8)	1	(3.8)	0	(0.0)	5	(1.8)
		1	(0.6)	0	(0.0)	1	(3.8)	0	(0.0)	2	(0.7)
		29	(17.3)	10	(14.1)	7	(26.9)	0	(0.0)	46	(16.6)
		47	(28.0)	20	(28.2)	7	(26.9)	4	(33.3)	78	(28.2)
		89	(53.0)	39	(54.9)	10	(38.5)	8	(66.7)	146	(52.7)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
19.	How often did your child's CRS doctors or other health providers explain things in a way you could understand?										
	Never	1	(0.6)	0	(0.0)	1	(3.8)	0	(0.0)	2	(0.7)
	Sometimes	8	(4.8)	3	(4.2)	2	(7.7)	0	(0.0)	13	(4.7)
	Usually	12	(7.1)	5	(7.0)	1	(3.8)	2	(16.7)	20	(7.2)
	Always	147	(87.5)	63	(88.7)	22	(84.6)	10	(83.3)	242	(87.4)
20.	How often did your child's CRS doctors or other health providers show respect for what you had to say?										
	Never	1	(0.6)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.4)
	Sometimes	12	(7.2)	2	(2.8)	2	(7.7)	0	(0.0)	16	(5.8)
	Usually	12	(7.2)	7	(9.9)	1	(3.8)	1	(8.3)	21	(7.6)
	Always	142	(85.0)	62	(87.3)	23	(88.5)	11	(91.7)	238	(86.2)
21.	How often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?										
	Never	2	(1.3)	0	(0.0)	0	(0.0)	0	(0.0)	2	(0.8)
	Sometimes	10	(6.7)	4	(6.5)	2	(8.7)	0	(0.0)	16	(6.6)
	Usually	14	(9.4)	5	(8.1)	1	(4.3)	2	(22.2)	22	(9.1)
	Always	123	(82.6)	53	(85.5)	20	(87.0)	7	(77.8)	203	(83.5)
22.	How often did you have your questions answered by your child's CRS doctors or other health providers?										
	Never	2	(1.3)	2	(3.2)	0	(0.0)	0	(0.0)	4	(1.6)
	Sometimes	11	(7.4)	4	(6.5)	2	(8.7)	0	(0.0)	17	(7.0)
	Usually	18	(12.1)	4	(6.5)	0	(0.0)	0	(0.0)	22	(9.1)
	Always	118	(79.2)	52	(83.9)	21	(91.3)	9	(100.0)	200	(82.3)
23.	How often did you get the specific information you needed from your child's CRS doctors or other health providers?										
	Never	2	(1.4)	1	(1.6)	1	(4.8)	0	(0.0)	4	(1.7)
	Sometimes	9	(6.5)	5	(8.1)	1	(4.8)	0	(0.0)	15	(6.6)
	Usually	19	(13.8)	5	(8.1)	2	(9.5)	1	(12.5)	27	(11.8)
	Always	108	(78.3)	51	(82.3)	17	(81.0)	7	(87.5)	183	(79.9)
24.	Were any decisions about your child's health care made during your CRS visits?										
	Yes	83	(49.4)	49	(68.1)	13	(50.0)	3	(25.0)	148	(53.2)
	No	85	(50.6)	23	(31.9)	13	(50.0)	9	(75.0)	130	(46.8)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
25.	When decisions were made, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?										
	Never	2	(2.4)	2	(4.1)	0	(0.0)	0	(0.0)	4	(2.7)
	Sometimes	9	(10.8)	3	(6.1)	0	(0.0)	0	(0.0)	12	(8.1)
	Usually	12	(14.5)	4	(8.2)	1	(7.7)	0	(0.0)	17	(11.5)
	Always	60	(72.3)	40	(81.6)	12	(92.3)	3	(100.0)	115	(77.7)
26.	When decisions were made, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?										
	Never	2	(2.4)	3	(6.3)	0	(0.0)	0	(0.0)	5	(3.4)
	Sometimes	10	(12.0)	3	(6.3)	0	(0.0)	0	(0.0)	13	(8.8)
	Usually	7	(8.4)	4	(8.3)	1	(7.7)	0	(0.0)	12	(8.2)
	Always	64	(77.1)	38	(79.2)	12	(92.3)	3	(100.0)	117	(79.6)
27.	When decisions were made, how often did your child's CRS doctors or other health providers involve you as much as you wanted?										
	Sometimes	3	(3.6)	2	(4.2)	0	(0.0)	0	(0.0)	5	(3.4)
	Usually	13	(15.7)	1	(2.1)	0	(0.0)	0	(0.0)	14	(9.5)
	Always	67	(80.7)	45	(93.8)	13	(100.0)	3	(100.0)	128	(87.1)
28.	What number would you use to rate your child's CRS care in the last 12 months?										
	Mean ± sd	9.0±1.9		9.2±1.2		9.0±1.6		9.3±1.1		9.0±1.7	
	0 - 3	6	(3.6)	0	(0.0)	0	(0.0)	0	(0.0)	6	(2.2)
	4 - 7	15	(8.9)	8	(11.1)	3	(11.5)	1	(8.3)	27	(9.7)
	8 - 10	147	(87.5)	64	(88.9)	23	(88.5)	11	(91.7)	245	(88.1)
29.	Did you need an interpreter to help you speak with your child's CRS doctors or other health providers?										
	Yes	54	(32.1)	12	(16.7)	0	(0.0)	7	(58.3)	73	(26.3)
	No	114	(67.9)	60	(83.3)	26	(100.0)	5	(41.7)	205	(73.7)
30.	When you needed an interpreter, how often did you get one?										
	Sometimes	4	(7.4)	0	(0.0)	0	(0.0)	0	(0.0)	4	(5.5)
	Usually	1	(1.9)	0	(0.0)	0	(0.0)	0	(0.0)	1	(1.4)
	Always	49	(90.7)	12	(100.0)	0	(0.0)	7	(100.0)	68	(93.2)

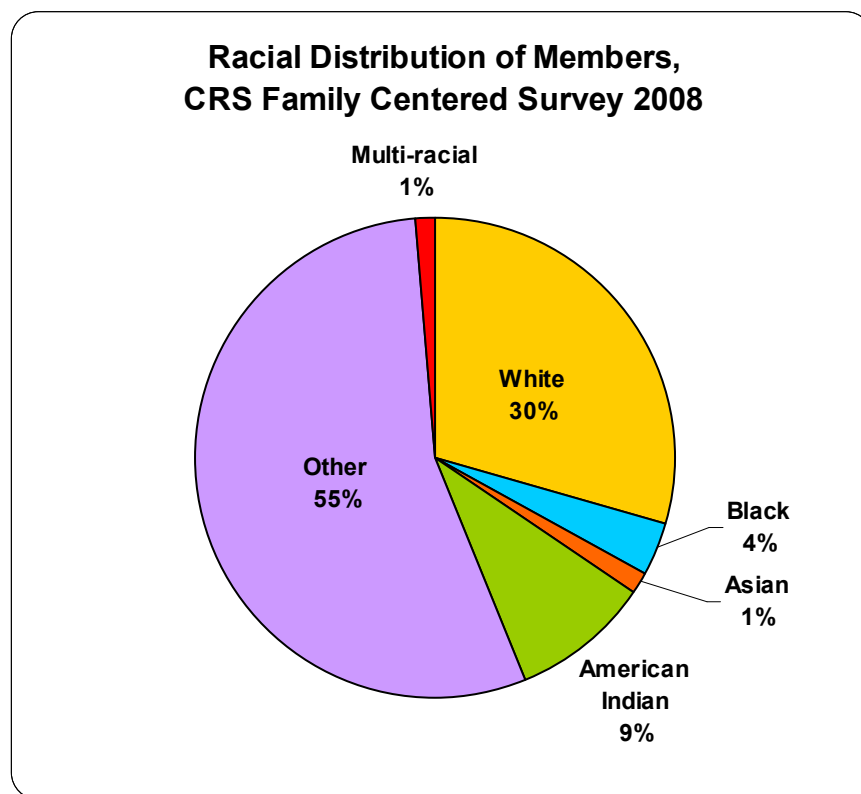
	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
31.	How would you rate your child's overall health now?										
	Excellent	47	(23.7)	27	(31.8)	9	(33.3)	6	(42.9)	89	(27.5)
	Very Good	69	(34.8)	29	(34.1)	9	(33.3)	7	(50.0)	114	(35.2)
	Good	61	(30.8)	20	(23.5)	5	(18.5)	1	(7.1)	87	(26.9)
	Fair	19	(9.6)	9	(10.6)	3	(11.1)	0	(0.0)	31	(9.6)
	Poor	2	(1.0)	0	(0.0)	1	(3.7)	0	(0.0)	3	(0.9)
32.	Is your child of Hispanic or Latino origin or descent?										
	Yes	117	(59.1)	53	(63.9)	6	(22.2)	11	(78.6)	187	(58.1)
	No	81	(40.9)	30	(36.1)	21	(77.8)	3	(21.4)	135	(41.9)
33.	What is your child's race?										
	White	56	(28.0)	24	(28.2)	8	(29.6)	3	(21.4)	91	(27.9)
	Black	9	(4.5)	2	(2.4)	0	(0.0)	0	(0.0)	11	(3.4)
	Asian	3	(1.5)	1	(1.2)	0	(0.0)	0	(0.0)	4	(1.2)
	American Indian	9	(4.5)	8	(9.4)	12	(44.4)	0	(0.0)	29	(8.9)
	Other	112	(56.0)	42	(49.4)	5	(18.5)	9	(64.3)	168	(51.5)
	Multi-racial	2	(1.0)	1	(1.2)	1	(3.7)	0	(0.0)	4	(1.2)
	Refused to answer	9	(4.5)	7	(8.2)	1	(3.7)	2	(14.3)	19	(5.8)
34.	What is the highest grade or level of school that you have completed?										
	8 th grade or less	24	(12.1)	4	(4.7)	2	(7.4)	0	(0.0)	30	(9.3)
	Some high school	46	(23.2)	10	(11.8)	3	(11.1)	2	(14.3)	61	(18.8)
	High school grad or GED	44	(22.2)	42	(49.4)	11	(40.7)	5	(35.7)	102	(31.5)
	Some college or 2-yr deg.	64	(32.3)	19	(22.4)	10	(37.0)	5	(35.7)	98	(30.2)
	4-yr college graduate	11	(5.6)	4	(4.7)	0	(0.0)	0	(0.0)	15	(4.6)
	More than 4-yr coll. degree	9	(4.5)	6	(7.1)	1	(3.7)	2	(14.3)	18	(5.6)
35.	What language do you mainly speak at home?										
	English	98	(49.0)	53	(62.4)	25	(92.6)	4	(28.6)	180	(55.2)
	Spanish	76	(38.0)	17	(20.0)	0	(0.0)	8	(57.1)	101	(31.0)
	English & Spanish	19	(9.5)	13	(15.3)	0	(0.0)	2	(14.3)	34	(10.4)
	Nonverbal	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.3)
	Arabic	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.3)
	Navajo	0	(0.0)	0	(0.0)	1	(3.7)	0	(0.0)	1	(0.3)
	Other/Unknown	5	(2.5)	2	(2.4)	1	(3.7)	0	(0.0)	8	(2.5)
36.	What language does your child mainly speak at home?										
	English	103	(51.5)	53	(62.4)	20	(74.1)	4	(28.6)	180	(55.2)
	Spanish	24	(12.0)	9	(10.6)	1	(3.7)	4	(28.6)	38	(11.7)
	English & Spanish	51	(25.5)	20	(23.5)	0	(0.0)	6	(42.9)	77	(23.6)
	Nonverbal	6	(3.0)	1	(1.2)	0	(0.0)	0	(0.0)	7	(2.1)
	Arabic	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.3)
	Navajo	0	(0.0)	0	(0.0)	1	(3.7)	0	(0.0)	1	(0.3)
	Sign language	4	(2.0)	0	(0.0)	0	(0.0)	0	(0.0)	4	(1.2)
	Not speaking yet	6	(3.0)	2	(2.4)	2	(7.4)	0	(0.0)	10	(3.1)
	Other/Unknown	5	(2.5)	0	(0.0)	3	(11.1)	0	(0.0)	8	(2.5)

	Question	Phoenix		Tucson		Flagstaff		Yuma		All	
37.	How are you related to the child?										
	Mother or father	179	(89.9)	77	(90.6)	25	(92.6)	13	(92.9)	294	(90.5)
	Grandparent	14	(7.0)	4	(4.7)	1	(3.7)	1	(7.1)	20	(6.2)
	Aunt or uncle	0	(0.0)	1	(1.2)	0	(0.0)	0	(0.0)	1	(0.3)
	Older brother or sister	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.3)
	Legal guardian	3	(1.5)	1	(1.2)	0	(0.0)	0	(0.0)	4	(1.2)
	Self	1	(0.5)	1	(1.2)	1	(3.7)	0	(0.0)	3	(0.9)
	Someone else	1	(0.5)	1	(1.2)	0	(0.0)	0	(0.0)	2	(0.6)

APPENDIX E: CULTURAL COMPETENCY EVALUATION

Culture can be defined as a shared, learned symbolic system of values, beliefs and attitudes that shape and influence perception and behavior. Culture is often taken for granted because it seems so natural and normal. Language is an important component of culture as is food, music, and religion. Culture is learned through social interaction and is most apparent when one violates taken-for-granted rules. Although culture is not directly observable, one can see its effects through behavior.

CRS serves many children who come from diverse cultural backgrounds. In the 2008 Family Centered Survey, it was estimated that 58 percent of CRS members represented by respondents were of Hispanic origin. As for the racial distribution, only 30 percent of the members were White, Non-Hispanic, with 70 percent of members belonging to a range of minority groups (see figure below).

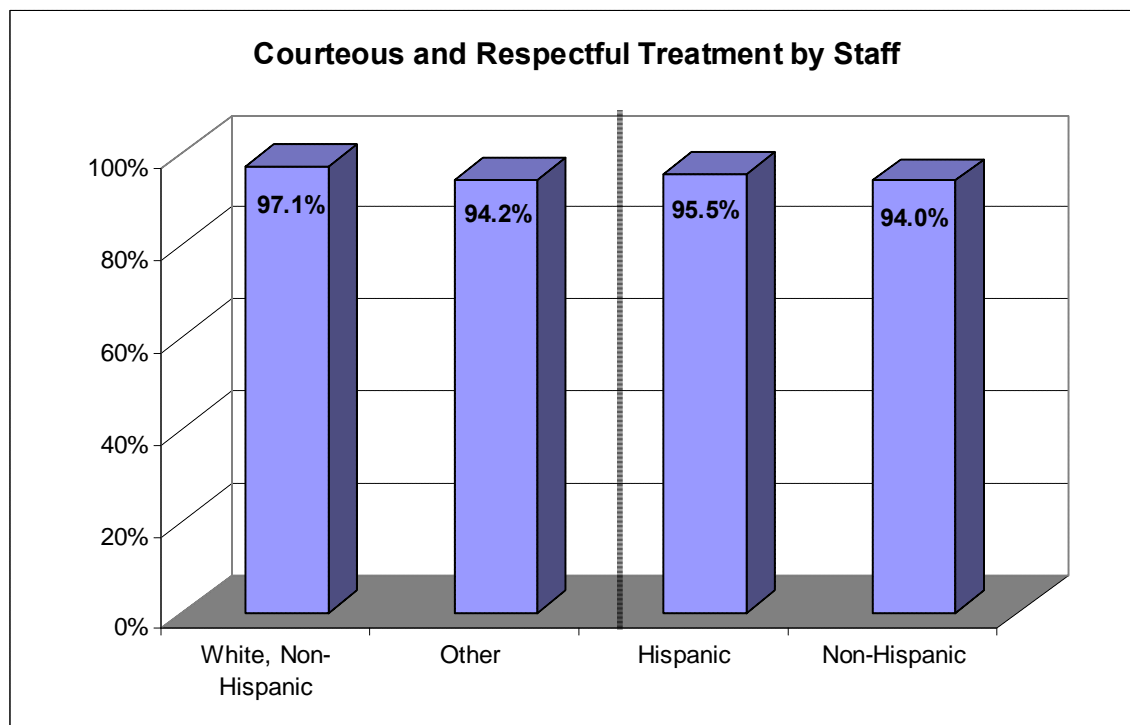


Cultural competency of CRS continues to be evaluated through the Family Centered Survey. The telephone survey included eight questions which directly related to cultural competency and five questions that were indirectly related. One way of assessing cultural competency is to evaluate differences between racial/ethnic groups. Results to each question were tabulated in order to compare White, Non-Hispanic members to those who are minorities, and Hispanic members to Non-Hispanic members. Comparisons to other races (Black, Asian, and American Indian) could not be made due to the small number of respondents within each group. Over-sampling may need to be performed in the future to obtain estimates for all races.

Among the results of the indirectly related questions, no statistical differences were found between Hispanic and Non-Hispanic members or between White, Non-Hispanics and other minorities. Tables showing these results are included at the end of the document. However, statistical differences were found between racial/ethnic groups for some of the directly related questions.

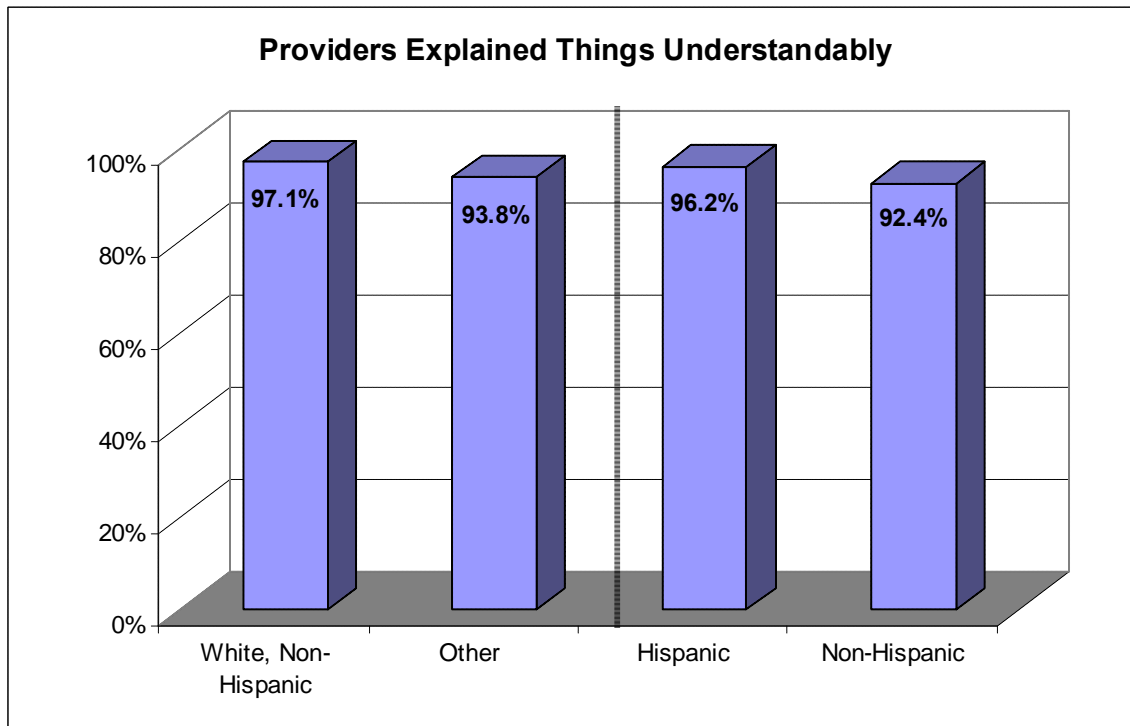
RESULTS (QUESTIONS DIRECTLY RELATED TO CULTURAL COMPETENCY)

Question 1: In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?



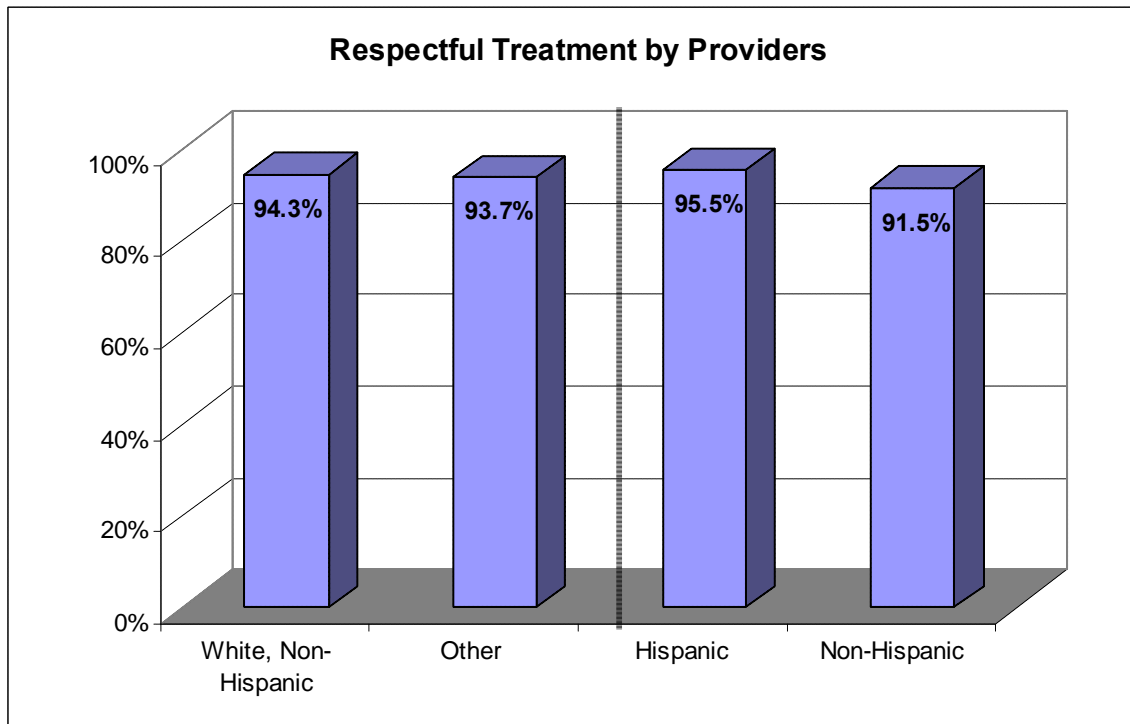
- In 2008, the vast majority of respondents in all four ethnic groups reported that they were usually or always treated with courtesy and respect by the CRS staff. No significant differences were found between Whites and minorities or between Hispanics and Non-Hispanics. The outcomes for this question were not statistically different from the outcomes in 2007.

Question 2: In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?



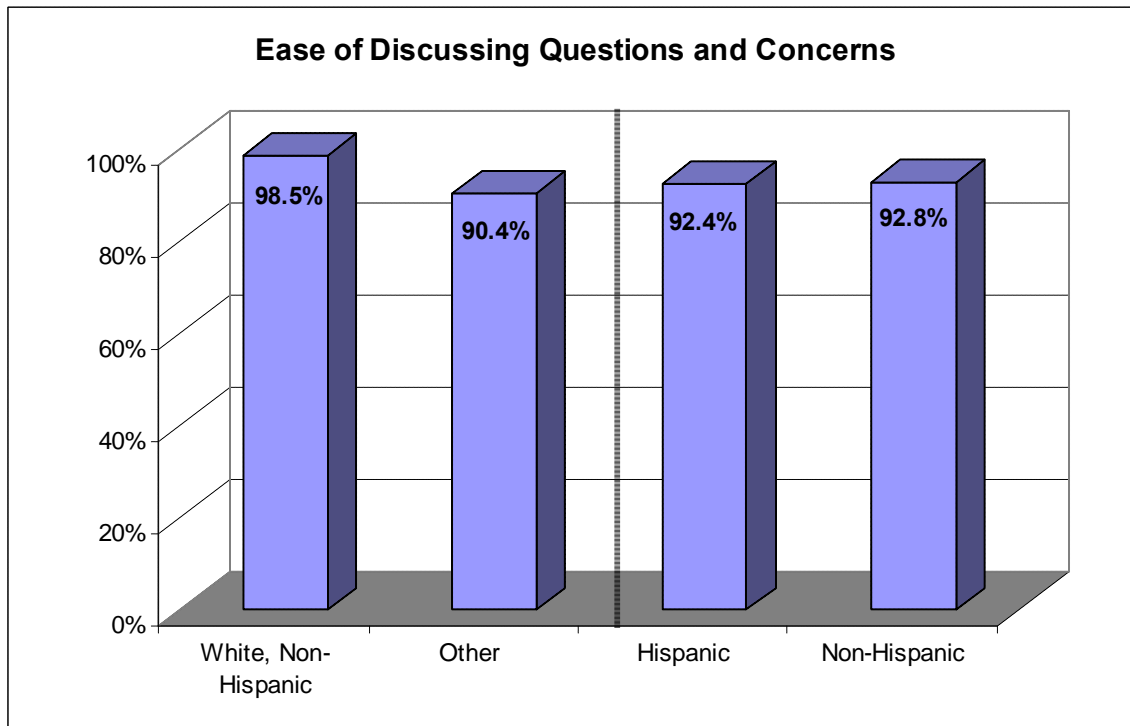
- A high percentage of respondents reported that CRS doctors and other health providers usually or always explained things understandably. No significant differences were found between Whites and minorities or between Hispanics and Non-Hispanics. The results of this question were not statistically different from the 2007 results.

Question 3: In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?



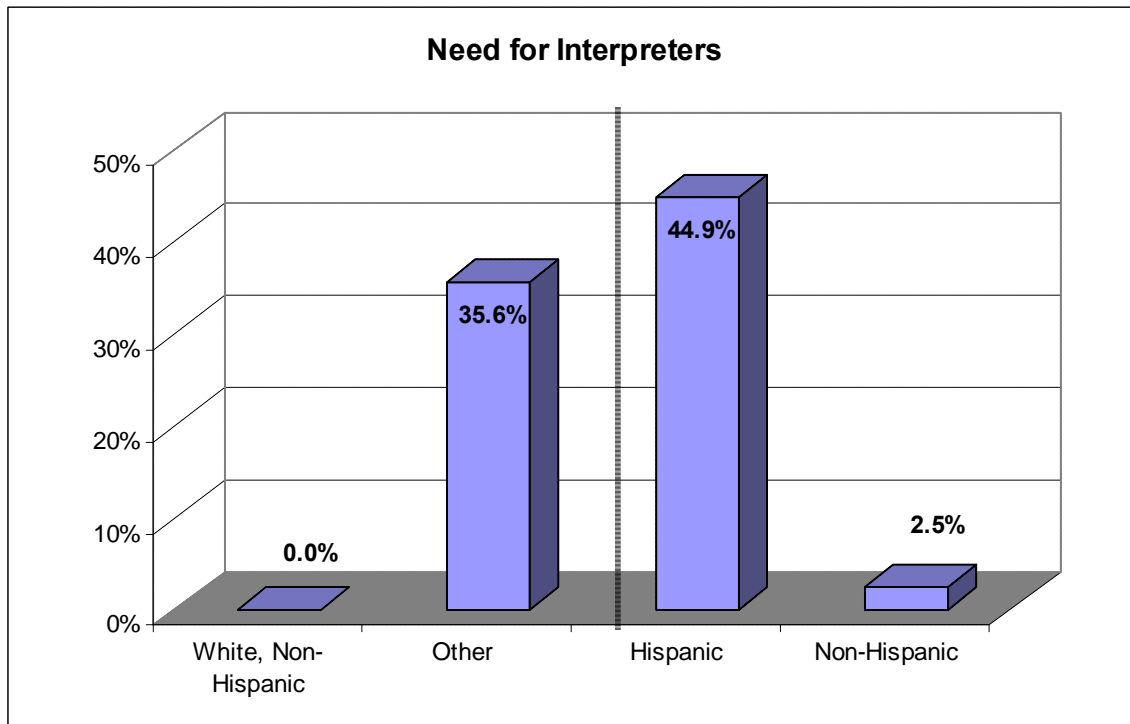
- In 2008, providers continued to show respect for what families had to say. Almost 96 percent of Hispanic families and 93.7 percent of minority families reported that they were usually or always treated with respect by CRS doctors and other health providers. No significant differences were found between Whites and minorities or between Hispanics and Non-Hispanics. The outcomes for this question were not statistically different from the outcomes in 2007.

Question 4: In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?



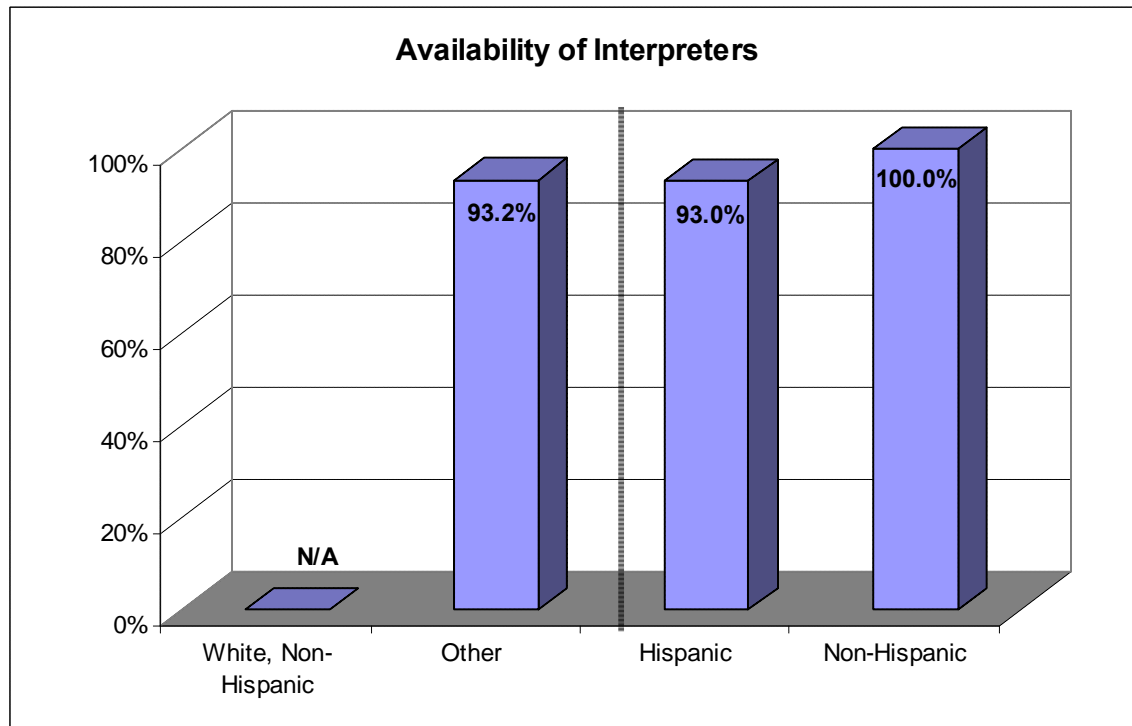
- Over 90 percent of member families contacted through the survey reported that it was usually or always easy to discuss their questions and concerns with providers. No significant differences were found between Whites and minorities or between Hispanics and Non-Hispanics. The results of this question were not statistically different from the 2007 results.

Question 5: In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?



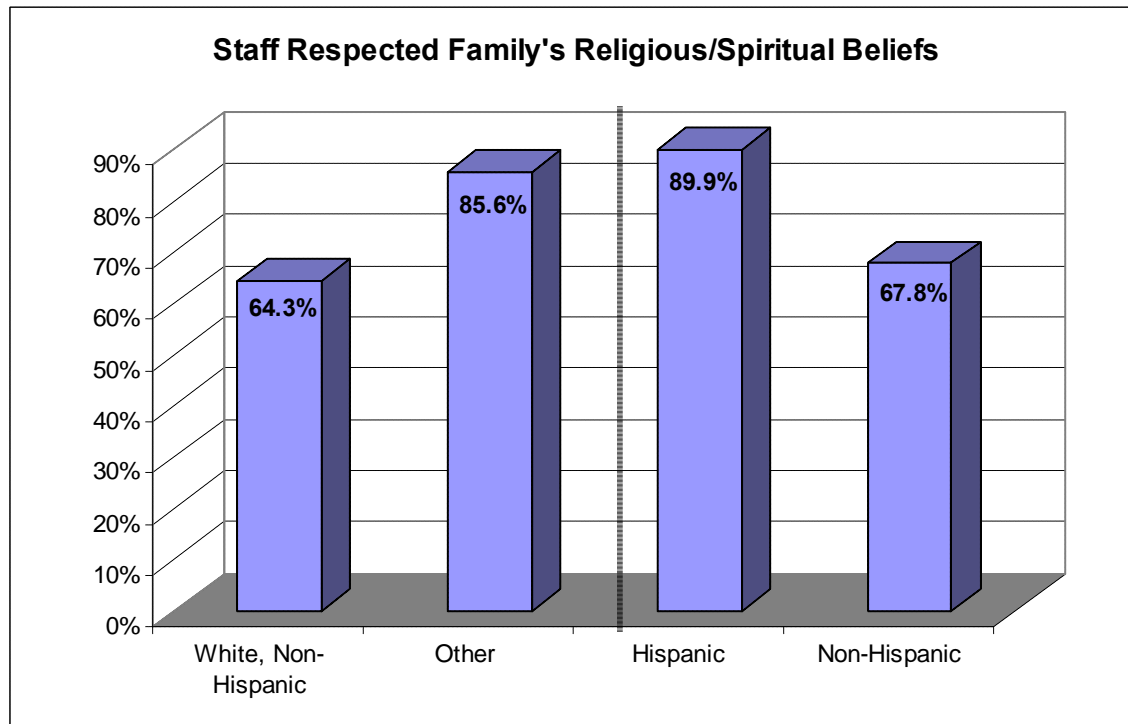
- Very few White and Non-Hispanic members needed an interpreter to assist them. However, almost half of Hispanic respondents (44.9%) needed an interpreter within the past year along with 35.6 percent of minorities.

Question 6: In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?



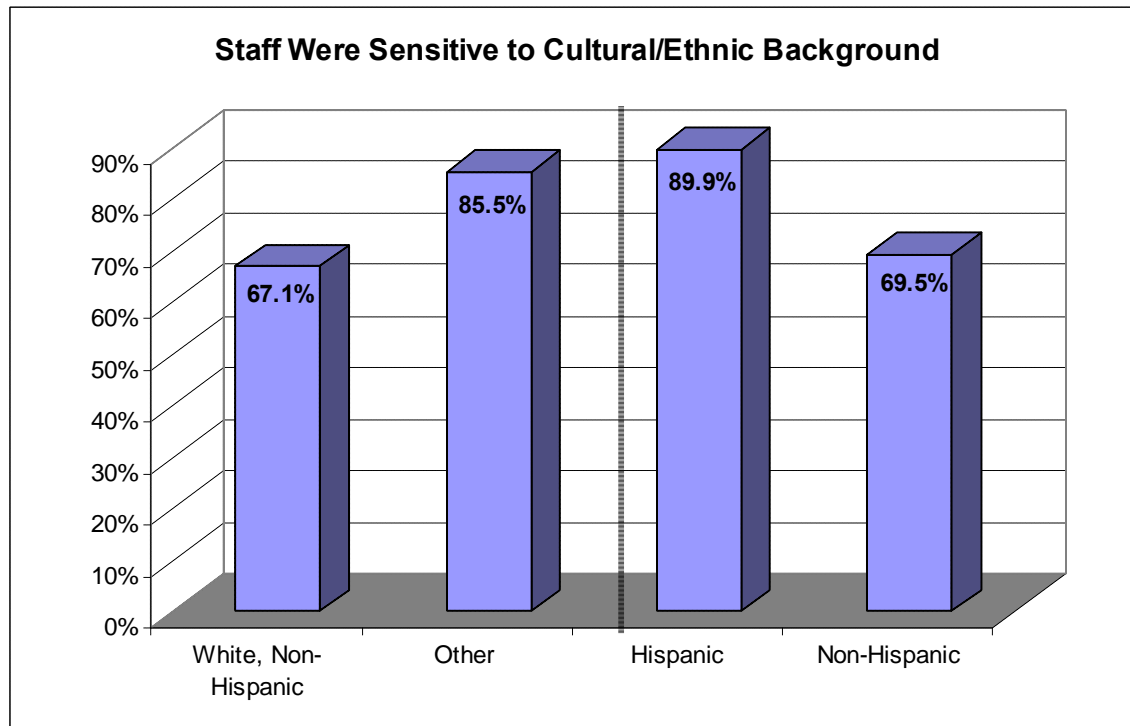
- Due to the small number of members who actually needed an interpreter, statistical differences between the racial/ethnic groups could not be concluded. Three Non-Hispanic respondents needed an interpreter and were always accommodated. The majority of minorities (93.2%) indicated that an interpreter was always available to them and 93 percent of Hispanics reported likewise. No White, Non-Hispanic members needed an interpreter.

Question 7: Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.



- This is one of two new questions that were added to the Family Centered Survey in 2007. It was taken from the Mental Health Statistics Improvement Program (MHSIP) Youth Services Survey. Respondents could choose a level of agreement with the statement from the following list: Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree.
- Statistical differences were found between racial/ethnic groups. The proportion of Hispanic families who agreed or strongly agreed that their religious/spiritual beliefs were respected by CRS staff was significantly higher than Non-Hispanic families. There was also a statistical difference between the White and the minority families' responses to this question.
- The 2008 results showed a significant increase in Hispanic and minority families who agreed or strongly agreed that the CRS staff respected their religious/spiritual beliefs compared to the 2007 results.
- A large number of respondents indicated that their religious/spiritual beliefs never came up in their clinic visits and thus answered "neutral" on the matter. This should be taken into consideration when interpreting these results.

Question 8: Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background.



- This was another question from MHSIP that was added to the survey in 2007. Statistical differences were found between racial/ethnic groups. Almost 90 percent of Hispanic families agreed or strongly agreed that CRS staff were sensitive to their cultural/ethnic background which was significantly higher than 69.5 percent of Non-Hispanic families. There was also a significant difference between the White and the minority families' responses to this question.
- The 2008 results showed a significant increase in Hispanic and minority families who agreed or strongly agreed that the CRS staff were sensitive to their cultural/ethnic background compared to the 2007 results.
- Again, many respondents reported that this issue "never came up" in their use of CRS services and often chose "neutral" as their response.

Results to Questions Indirectly Related to Cultural Competency

Table 1. Helpful Staff vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?	Never	Count	0	2	2
		% within Hispanic or Latino descent	.0%	1.3%	.7%
	Sometimes	Count	11	8	19
		% within Hispanic or Latino descent	9.3%	5.1%	6.9%
	Usually	Count	19	11	30
		% within Hispanic or Latino descent	16.1%	7.0%	10.9%
	Always	Count	88	137	225
		% within Hispanic or Latino descent	74.6%	86.7%	81.5%
	Total	Count	118	158	276
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 2. Listens vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how often did the CRS clinic staff listen carefully to you?	Never	Count	1	2	3
		% within Hispanic or Latino descent	.8%	1.3%	1.1%
	Sometimes	Count	12	6	18
		% within Hispanic or Latino descent	10.2%	3.8%	6.6%
	Usually	Count	20	15	35
		% within Hispanic or Latino descent	16.9%	9.6%	12.8%
	Always	Count	85	133	218
		% within Hispanic or Latino descent	72.0%	85.3%	79.6%
	Total	Count	118	156	274
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 3. Providers Answer Questions vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?	Never	Count	1	3	4
		% within Hispanic or Latino descent	.9%	2.3%	1.7%
	Sometimes	Count	8	9	17
		% within Hispanic or Latino descent	7.2%	6.9%	7.0%
	Usually	Count	10	13	23
		% within Hispanic or Latino descent	9.0%	9.9%	9.5%
	Always	Count	92	106	198
		% within Hispanic or Latino descent	82.9%	80.9%	81.8%
	Total	Count	111	131	242
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 4. Providers Give Information vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?	Never	Count	2	2	4
		% within Hispanic or Latino descent	1.8%	1.7%	1.8%
	Sometimes	Count	8	7	15
		% within Hispanic or Latino descent	7.3%	5.9%	6.6%
	Usually	Count	16	11	27
		% within Hispanic or Latino descent	14.7%	9.3%	11.9%
	Always	Count	83	98	181
		% within Hispanic or Latino descent	76.1%	83.1%	79.7%
	Total	Count	109	118	227
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 5. Providers Offer Choices vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?	Never	Count	1	3	4
		% within Hispanic or Latino descent	1.3%	4.3%	2.7%
	Sometimes	Count	6	6	12
		% within Hispanic or Latino descent	7.8%	8.6%	8.2%
	Usually	Count	9	8	17
		% within Hispanic or Latino descent	11.7%	11.4%	11.6%
	Always	Count	61	53	114
		% within Hispanic or Latino descent	79.2%	75.7%	77.6%
	Total	Count	77	70	147
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 6. Helpful Staff, White vs. Other

			White vs. Other		
			Other	White, Non-Hispanic	Total
In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?	Never	Count	2	0	2
		% within White vs. Other	1.0%	.0%	.7%
	Sometimes	Count	14	5	19
		% within White vs. Other	6.7%	7.1%	6.8%
	Usually	Count	18	12	30
		% within White vs. Other	8.7%	17.1%	10.8%
	Always	Count	174	53	227
		% within White vs. Other	83.7%	75.7%	81.7%
	Total	Count	208	70	278
		% within White vs. Other	100.0%	100.0%	100.0%

Table 7. Staff Listens, White vs. Other

			White vs. Other		Total
			Other	White, Non-Hispanic	
In the last 12 months, how often did the CRS clinic staff listen carefully to you?	Never	Count	3	0	3
		% within White vs. Other	1.5%	.0%	1.1%
	Sometimes	Count	11	7	18
		% within White vs. Other	5.3%	10.0%	6.5%
	Usually	Count	18	17	35
		% within White vs. Other	8.7%	24.3%	12.7%
	Always	Count	174	46	220
		% within White vs. Other	84.5%	65.7%	79.7%
Total	Count		206	70	276
	% within White vs. Other		100.0%	100.0%	100.0%

Table 8. Providers Answer Questions, White vs. Other

			White vs. Other		Total
			Other	White, Non-Hispanic	
In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?	Never	Count	4	0	4
		% within White vs. Other	2.3%	.0%	1.6%
	Sometimes	Count	14	3	17
		% within White vs. Other	8.0%	4.4%	7.0%
	Usually	Count	16	7	23
		% within White vs. Other	9.1%	10.3%	9.4%
	Always	Count	142	58	200
		% within White vs. Other	80.7%	85.3%	82.0%
Total	Count		176	68	244
	% within White vs. Other		100.0%	100.0%	100.0%

Table 9. Providers Give Information, White vs. Other

			White vs. Other		Total
			Other	White, Non-Hispanic	
In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?	Never	Count	3	1	4
		% within White vs. Other	1.8%	1.5%	1.7%
	Sometimes	Count	11	4	15
		% within White vs. Other	6.7%	6.2%	6.6%
	Usually	Count	16	11	27
		% within White vs. Other	9.8%	16.9%	11.8%
	Always	Count	134	49	183
		% within White vs. Other	81.7%	75.4%	79.9%
Total	Count		164	65	229
	% within White vs. Other		100.0%	100.0%	100.0%

Table 10. Providers Offer Choices, White vs. Other

			White vs. Other		Total
			Other	White, Non-Hispanic	
When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?	Never	Count	3	1	4
		% within White vs. Other	2.8%	2.4%	2.7%
	Sometimes	Count	10	2	12
		% within White vs. Other	9.4%	4.8%	8.1%
	Usually	Count	13	4	17
		% within White vs. Other	12.3%	9.5%	11.5%
	Always	Count	80	35	115
		% within White vs. Other	75.5%	83.3%	77.7%
	Total	Count	106	42	148
		% within White vs. Other	100.0%	100.0%	100.0%

Results to Questions Directly Related to Cultural Competency

Table 11. Courteous and Respectful Treatment by Staff vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		Total
			No	Yes	
In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?	Never	Count	1	2	3
		% within Hispanic or Latino descent	.8%	1.3%	1.1%
	Sometimes	Count	6	5	11
		% within Hispanic or Latino descent	5.1%	3.2%	4.0%
	Usually	Count	7	6	13
		% within Hispanic or Latino descent	5.9%	3.8%	4.7%
	Always	Count	104	144	248
		% within Hispanic or Latino descent	88.1%	91.7%	90.2%
	Total	Count	118	157	275
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 12. Ease of Discussing Questions and Concerns vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?	Never	Count	1	1	2
		% within Hispanic or Latino descent	.9%	.8%	.8%
	Sometimes	Count	7	9	16
		% within Hispanic or Latino descent	6.3%	6.9%	6.6%
	Usually	Count	11	11	22
		% within Hispanic or Latino descent	9.9%	8.4%	9.1%
	Always	Count	92	110	202
		% within Hispanic or Latino descent	82.9%	84.0%	83.5%
	Total	Count	111	131	242
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 13. Understanding Providers vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?	Never	Count	2	0	2
		% within Hispanic or Latino descent	1.7%	.0%	.7%
	Sometimes	Count	7	6	13
		% within Hispanic or Latino descent	5.9%	3.8%	4.7%
	Usually	Count	13	7	20
		% within Hispanic or Latino descent	11.0%	4.4%	7.2%
	Always	Count	96	145	241
		% within Hispanic or Latino descent	81.4%	91.8%	87.3%
	Total	Count	118	158	276
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 14. Respectful Treatment by Providers vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		Total
			No	Yes	
In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?	Never	Count	0	1	1
		% within Hispanic or Latino descent	.0%	.6%	.4%
	Sometimes	Count	10	6	16
		% within Hispanic or Latino descent	8.5%	3.8%	5.8%
	Usually	Count	9	12	21
		% within Hispanic or Latino descent	7.6%	7.6%	7.6%
	Always	Count	99	138	237
		% within Hispanic or Latino descent	83.9%	87.9%	86.2%
	Total	Count	118	157	275
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 15. Need for Interpreters vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		Total
			No	Yes	
In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?	No	Count	116	87	203
		% within Hispanic or Latino descent	97.5%	55.1%	73.3%
	Yes	Count	3	71	74
		% within Hispanic or Latino descent	2.5%	44.9%	26.7%
	Total	Count	119	158	277
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 16. Availability of Interpreters vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?	Sometimes	Count	0	4	4
		% within Hispanic or Latino descent	.0%	5.6%	5.4%
	Usually	Count	0	1	1
		% within Hispanic or Latino descent	.0%	1.4%	1.4%
	Always	Count	3	66	69
		% within Hispanic or Latino descent	100.0%	93.0%	93.2%
Total	Count	3	71	74	
	% within Hispanic or Latino descent	100.0%	100.0%	100.0%	

Table 17. Staff respected my family's religious/spiritual beliefs. (Ethnicity)

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.	Strongly Disagree	Count	4	0	4
		% within Hispanic or Latino descent	3.4%	.0%	1.4%
	Neutral	Count	34	16	50
		% within Hispanic or Latino descent	28.8%	10.1%	18.1%
	Agree	Count	30	40	70
		% within Hispanic or Latino descent	25.4%	25.3%	25.4%
	Strongly Agree	Count	50	102	152
		% within Hispanic or Latino descent	42.4%	64.6%	55.1%
Total	Count	118	158	276	
	% within Hispanic or Latino descent	100.0%	100.0%	100.0%	

Table 18. Staff were sensitive to my cultural/ethnic background. (Ethnicity)

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background.	Strongly Disagree	Count	4	1	5
		% within Hispanic or Latino descent	3.4%	.6%	1.8%
	Disagree	Count	2	0	2
		% within Hispanic or Latino descent	1.7%	.0%	.7%
	Neutral	Count	30	15	45
		% within Hispanic or Latino descent	25.4%	9.5%	16.3%
	Agree	Count	32	46	78
		% within Hispanic or Latino descent	27.1%	29.1%	28.3%
	Strongly Agree	Count	50	96	146
		% within Hispanic or Latino descent	42.4%	60.8%	52.9%
Total		Count	118	158	276
		% within Hispanic or Latino descent	100.0%	100.0%	100.0%

Table 19. Courteous and Respectful Treatment by Staff, White vs. Other

			White vs. Other		
			Other	White, Non-Hispanic	Total
In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?	Never	Count	2	1	3
		% within White vs. Other	1.0%	1.4%	1.1%
	Sometimes	Count	10	1	11
		% within White vs. Other	4.8%	1.4%	4.0%
	Usually	Count	8	5	13
		% within White vs. Other	3.9%	7.1%	4.7%
	Always	Count	187	63	250
		% within White vs. Other	90.3%	90.0%	90.3%
Total		Count	207	70	277
		% within White vs. Other	100.0%	100.0%	100.0%

Table 20. Ease of Discussing Questions and Concerns, White vs. Other

			White vs. Other		Total
			Other	White, Non-Hispanic	
In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?	Never	Count	2	0	2
		% within White vs. Other	1.1%	.0%	.8%
	Sometimes	Count	15	1	16
		% within White vs. Other	8.5%	1.5%	6.6%
	Usually	Count	13	9	22
		% within White vs. Other	7.4%	13.2%	9.0%
	Always	Count	146	58	204
		% within White vs. Other	83.0%	85.3%	83.6%
	Total	Count	176	68	244
		% within White vs. Other	100.0%	100.0%	100.0%

Table 21. Understanding Providers, White vs. Other

			White vs. Other		Total
			Other	White, Non-Hispanic	
In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?	Never	Count	2	0	2
		% within White vs. Other	1.0%	.0%	.7%
	Sometimes	Count	11	2	13
		% within White vs. Other	5.3%	2.9%	4.7%
	Usually	Count	10	10	20
		% within White vs. Other	4.8%	14.3%	7.2%
	Always	Count	185	58	243
		% within White vs. Other	88.9%	82.9%	87.4%
	Total	Count	208	70	278
		% within White vs. Other	100.0%	100.0%	100.0%

Table 22. Respectful Treatment by Providers, White vs. Other

			White vs. Other		Total
			Other	White, Non-Hispanic	
In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?	Never	Count	1	0	1
		% within White vs. Other	.5%	.0%	.4%
	Sometimes	Count	12	4	16
		% within White vs. Other	5.8%	5.7%	5.8%
	Usually	Count	15	6	21
		% within White vs. Other	7.2%	8.6%	7.6%
	Always	Count	179	60	239
		% within White vs. Other	86.5%	85.7%	86.3%
	Total	Count	207	70	277
		% within White vs. Other	100.0%	100.0%	100.0%

Table 23. Need for Interpreters, White vs. Other

			White vs. Other		
			Other	White, Non-Hispanic	Total
In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?	No	Count	134	71	205
		% within White vs. Other	64.4%	100.0%	73.5%
	Yes	Count	74	0	74
		% within White vs. Other	35.6%	.0%	26.5%
Total		Count	208	71	279
		% within White vs. Other	100.0%	100.0%	100.0%

Table 24. Availability of Interpreters, White vs. Other

			White vs. Other	
			Other	Total
In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?	Sometimes	Count	4	4
		% within White vs. Other	5.4%	5.4%
	Usually	Count	1	1
		% within White vs. Other	1.4%	1.4%
	Always	Count	69	69
		% within White vs. Other	93.2%	93.2%
Total	Count	74	74	
	% within White vs. Other	100.0%	100.0%	

Table 25. Staff respected my family's religious/spiritual beliefs. (White vs. Other)

			White vs. Other		Total
			Other	White, Non-Hispanic	
Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.	Strongly Disagree	Count	2	2	4
		% within White vs. Other	1.0%	2.9%	1.4%
	Neutral	Count	28	23	51
		% within White vs. Other	13.5%	32.9%	18.3%
	Agree	Count	54	16	70
		% within White vs. Other	26.0%	22.9%	25.2%
	Strongly Agree	Count	124	29	153
		% within White vs. Other	59.6%	41.4%	55.0%
Total	Count	208	70	278	
	% within White vs. Other	100.0%	100.0%	100.0%	

Table 26. Staff were sensitive to my cultural/ethnic background. (White vs. Other)

			White vs. Other		
			Other	White, Non-Hispanic	Total
Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background.	Strongly Disagree	Count	2	3	5
		% within White vs. Other	1.0%	4.3%	1.8%
	Disagree	Count	1	1	2
		% within White vs. Other	.5%	1.4%	.7%
	Neutral	Count	27	19	46
		% within White vs. Other	13.0%	27.1%	16.5%
	Agree	Count	60	18	78
		% within White vs. Other	28.8%	25.7%	28.1%
	Strongly Agree	Count	118	29	147
		% within White vs. Other	56.7%	41.4%	52.9%
Total	Count	208	70	278	
	% within White vs. Other	100.0%	100.0%	100.0%	